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“the Littlest Victims”: Pediatric Aids And The Urban Ecology Of Health In The Late-Twentieth-Century United States

Abstract

“The Littlest Victims” tells the untold history of children with AIDS, their families, and their caregivers while examining the structural causes, rise, and decline of pediatric AIDS in the U.S. from the 1950s through the early 2000s. This history complements and complicates the grand narrative of AIDS in the United States, one largely focused on how gay men and AIDS activists coped with, and influenced, the nation’s response to AIDS. Not only did HIV-AIDS affect children differently, pediatric AIDS disproportionately affected families of color living in poor urban environments. In this respect, the history of pediatric AIDS is inseparable from how Americans perceived and responded to urban poverty in the late twentieth century. My dissertation thus explores the relationship between HIV-AIDS, families of color, and the urban spaces in which pediatric AIDS was most prevalent. It argues that the physical and social environments that structured the experiences of families of color living in poor urban neighborhoods defined the realities and perceptions of pediatric AIDS. Pediatric AIDS arose from the post-World War II urban geographies of concentrated poverty, racialized segregation, and urban-renewal policies, creating an ecology where HIV-transmission proliferated in the late 1970s and early 1980s. Then, as pediatric AIDS gained scientific, public health, cultural, and political visibility during the mid 1980s and early 1990s, it became inextricably linked to the real and imagined problems of the “inner city.” This cultural framing of pediatric AIDS profoundly influenced the way Americans understood and responded to the disease among children and their families. From the late 1980s to the early 2000s, teams of nurses navigated the complexities of caring for sick children alongside the problems of poverty that challenged caregivers in the home and hospital. During those same years, the advent of antiretroviral medications proved effective in drastically reducing the transmission of HIV in utero and at birth. However, the success of such biomedical solutions to pediatric AIDS had a paradoxical effect: the “medical-progress” narratives that accompanied these advances unintentionally undermined community-based efforts to address the larger social, economic, and environmental factors that put children at risk for HIV-AIDS in the first place.

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David S. Barnes

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Cynthia A. Connolly

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“THE LITTLEST VICTIMS”:
PEDIATRIC AIDS AND THE URBAN ECOLOGY OF HEALTH IN THE LATE-TWENTIETH-
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Jason Michael Chernesky

A DISSERTATION

in

History and Sociology of Science

Presented to the Faculties of the University of Pennsylvania

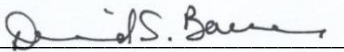
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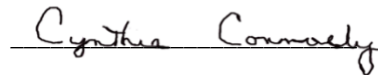
Supervisor of Dissertation



David S. Barnes

Associate Professor
History and Sociology of Science

Co-Supervisor of Dissertation



Cynthia A. Connolly

Professor of Nursing
School of Nursing

Graduate Group Chairperson



Adelheid Voskuhl
Associate Professor, History and Sociology of Science

Dissertation Committee

Beth Linker, Associate Professor, History and Sociology of Science

Michael Yudell, Professor, Dornsife School of Public Health, Drexel University

“THE LITTLEST VICTIMS”:
PEDIATRIC AIDS AND THE URBAN ECOLOGY OF HEALTH IN THE LATE-
TWENTIETH CENTURY UNITED STATES

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Jason Michael Chernesky

DEDICATION

To the American children and families who died from HIV-AIDS

This dissertation is also dedicated to:

Cynthia Connolly, Stephen Pemberton, David Barnes, Vivian Thiele and, especially,

Alicia Juarez

Their support helped me persevere

ABSTRACT

“THE LITTLEST VICTIMS”:

PEDIATRIC AIDS AND THE URBAN ECOLOGY OF HEALTH IN THE LATE-TWENTIETH CENTURY UNITED STATES

Jason Michael Chernesky

David S. Barnes

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INTRODUCTION

In early April of 1990, NBC's *Nightly News* showed the pop-music singer Michael Jackson, and the wealthy real-estate businessman Donald Trump, approaching the door of a small Indiana home. As the door opened, with Mr. Trump looking on, Mr. Jackson immediately embraced a weeping Jeanne White. Jeanne had just lost her son, Ryan, who died from complications due to AIDS after contracting the disease through an HIV-contaminated blood product. By that point, Ryan White had become a celebrity in his own right: his courageous campaign to de-stigmatize AIDS, in the preceding years, had made him into an important national figure. While Ryan was known and supported by thousands around the world, he was also just one of thousands of young people who lived with, or were dying from, AIDS in the United States.¹

Although Ryan became the most well-known, celebrated, and remembered pediatric AIDS patient, he did not represent most young Americans with the disease. Ryan White's story therefore illuminates an important paradox in the history of AIDS in the United States. Most children with the disease were Black or Latinx, under the age of thirteen, were born with HIV, and lived in cities like Newark, New Jersey, the Bronx, New York, Miami, Florida, San Juan, Puerto Rico, or Washington DC.² Yet these children, and their families, remain marginalized in our historical understanding of the AIDS epidemic in the United States. This dissertation removes those children and families from the margins and places their stories at the center of the history of AIDS in

¹ "Death of Ryan White," *NBC Nightly News*, Sunday, April 8, 1990, Vanderbilt Television News Archives (hereafter cited; VTNA).

² For the epidemiology of pediatric AIDS in the United States by the time of Ryan White's death, see for example, Margaret J. Oxtoby, "Perinatally Acquired HIV Infection," in Philip A. Pizzo and Catherine M. Wilfert, eds., *Pediatric AIDS: The Challenge of HIV Infection in Infants, Children, and Adolescents* (Baltimore: Williams & Wilkins, 1991).

America. In doing so, my goal is to illuminate the overshadowed, and under-researched, history of pediatric AIDS; in particular, how this history intersects with age, race, and place during the late twentieth century.

By focusing on children with HIV, my dissertation is the first comprehensive historical analysis of pediatric AIDS in the United States. Most importantly, this dissertation argues that understanding the connections between pediatric AIDS and place, specifically urban landscapes, is crucial to any historical analysis of HIV-AIDS among children and their families. As this dissertation shows, we cannot disentangle one from the other. I argue that the problem of pediatric AIDS in the U.S. was defined by, and the result of, the physical and social environments that structured the lives of families of color in poor urban spaces. In this respect, pediatric AIDS provides a historical lens that reveals the links between the emergence of HIV with the drastically changing and racially segregated urban ecologies of the post-World War II years. We also see how medical institutions and their people in New York City, Miami, and especially Newark — the three epicenters of pediatric AIDS — factored prominently in developing important healthcare responses to HIV-AIDS among children. Perhaps most notably, the real and imagined problems of “the inner city,” a foreign landscape to many Americans, became inextricably linked to the problem of pediatric AIDS. Popular perceptions about late-twentieth-century urban poverty structured the way Americans saw and responded to the HIV-AIDS among children and their families.

My focus on pediatric AIDS also helps expand our scholarly analysis about the AIDS epidemic in the U.S.. Standard narratives and analyses about the epidemic have focused on the ways in which HIV-AIDS has affected adults — most notably, gay men.

But children experienced the disease differently than adults. Unlike adults, children could not care for themselves, they could not seek medical attention on their own, and the disease hindered their development. Since most of the children with AIDS were infants or toddlers, they relied on a host of adults that cared for them, advocated for them, and eventually helped prevent HIV from infecting other children. This dissertation thus necessarily uses the documents of these adults in telling the story of pediatric AIDS. This history emerged from the personal accounts, published materials, and cultural artifacts produced by nurses, physicians, public health professionals, social workers, journalists, policymakers, politicians, parents, foster families, and grandmothers; many of whom coped with, and sought solutions for, the problem of pediatric AIDS.

Through their work and experience, this dissertation compels us to interrogate the role children, especially infants, played as historical actors in our understanding of the AIDS epidemic. Infants, for example, do not possess the typical types of agency associated with older children or adults. But neither are babies powerless. Their actions — dying, suffering, growing — and how adults react to them, further reveals how the nation has responded to sick and dying children, and which at-risk children are considered a national priority.³ The history of pediatric AIDS is crucial in this respect. The tapestry of experiences and actors in my dissertation thus reveals that age is a critical, yet underrepresented category of analysis in understanding the history of the AIDS epidemic in the United States.

³ Janet Lynne Golden, *Babies Made Us Modern : How Infants Brought America into the Twentieth Century* (New York, NY: Cambridge University Press, 2018).

During the late 1970s and early 1980s, pediatricians in Newark, New York City and Miami began witnessing strange illnesses in a few pediatric patients. In 1982, the first child with HIV-AIDS was identified. That child contracted the disease through HIV-contaminated blood. In the spring of 1983, two physicians — Dr. James Oleske and Arye Rubinstein — published what became the first cases of children born with HIV-AIDS. These important events in the history of pediatric AIDS are told in the book *The AIDS Doctors: Voices from the Epidemic* (2000). The authors, Ronald Bayer and Gerald Oppenheimer, collected dozens of oral histories from physicians who had cared for adult and pediatric patients with HIV-AIDS. But the book is more than just a collection of oral histories. For those engaging with the history of the AIDS in the United States, *The AIDS Doctors* is an important account of how the epidemic unfolded, and how the medical community responded to the disease. The pediatricians that identified the first case of pediatric AIDS, and who in turn cared for those patients, are part of Bayer and Oppenheimer's history.⁴

The story of children with AIDS is certainly part of that medical history, but as we engage with and move beyond accounts of physicians, a much broader understanding of pediatric AIDS emerges. Despite the voluminous scholarly and popular literature about the AIDS epidemic, pediatric AIDS has escaped critical, historical analysis. Of course, the medical and public health histories of HIV-AIDS are critical in understanding the story of pediatric AIDS. Pediatricians played an important role in developing models of care for children with HIV-AIDS, caring for those children, and helping develop

⁴ Ronald Bayer and Gerald M. Oppenheimer, *AIDS Doctors : Voices from the Epidemic* (New York: Oxford University Press, 2000).

prevention interventions that eventually led to a drastic decrease in pediatric AIDS during the late 1990s and early 2000s.⁵

But as we explore the history of pediatric AIDS, we see that the maintenance and care of children with AIDS relied on a broader set of people that worked within and outside the walls of the hospital. Just as there were “AIDS doctors,” there were also “AIDS nurses.” Much of the historiography of AIDS in the U.S. have eschewed analyses of the role nurses played in caring for patients with the disease. Nurses were central to the care of AIDS patients, especially in the years before effective antiretroviral medications transformed AIDS from a deadly disease into a chronic illness. In the history of pediatric AIDS, nurses were particularly important. They not only cared for pediatric patients with the disease, but they also helped develop important systems of care that became central to the management of HIV-AIDS in children.⁶

⁵ The following is a selection of scholarship on HIV-AIDS. I highlight some other works below, and there are some scholarly accounts of HIV-AIDS that I use in the dissertation that are not listed in the introduction: Allan Brandt, “AIDS: From Social History to Social Policy,” *Law, Medicine, and Health Care*, 15, no. 5 (December 1986): 5-6. Elizabeth Fee and Daniel M. Fox, eds., *AIDS: The Burdens of History* (Berkeley: University of California Press, 1988); Sander L. Gilman, *Disease and Representation: Images of Illness from Madness to AIDS* (Ithaca: Cornell University Press, 1988); Ronald Bayer, *Private Acts, Social Consequences: AIDS and the Politics of Public Health* (New York: Free Press, 1989); Mirko D. Grmek, *History of AIDS: Emergence and Origin of a Modern Pandemic* (Princeton, N.J.: Princeton University Press, 1990); Elizabeth Fee and Daniel M. Fox, eds., *AIDS: The Making of a Chronic Disease* (Berkeley: University of California Press, 1992); Charles E. Rosenberg, *Explaining Epidemics and Other Studies in the History of Medicine* (New York: Cambridge University Press, 1992); Virginia Berridge and Philip Strong, eds., *AIDS and Contemporary History*, (Cambridge: Cambridge University Press, 1993); Steven Epstein, *Impure Science: AIDS, Activism, and the Politics of Knowledge* (Berkeley: University of California Press, 1996); Paula A. Triechler, *How to Have Theory in an Epidemic: Cultural Chronicles of AIDS* (Durham: Duke University Press, 1999); Eric A. Feldman and Ronald Bayer, eds., *Blood Feuds: AIDS, Blood, and the Politics of Medical Disaster* (New York: Oxford University Press, 1999); Peter Baldwin, *Disease and Democracy: The Industrialized World Faces AIDS* (Berkeley: University of California Press, 2005); Lawrence O. Gostin, *The AIDS Pandemic Complacency, Injustice, and Unfulfilled Expectations* (Chapel Hill: University of North Carolina Press, 2003). David L. Kirp, *Learning by Heart: AIDS and Schoolchildren in America's Communities* (New Brunswick: Rutgers University Press, 1989); Arthur J. Ammann, *Lethal Decisions: The Unnecessary Deaths of Women and Children from HIV/AIDS* (Nashville: Vanderbilt University Press, 2017).

⁶ Susan Reverby, *Ordered to Care: The Dilemma of American Nursing, 1850-1945* (Cambridge University Press, 1987); Charles E. Rosenberg, *The Care of Strangers: The Rise of America's Hospital System* (New

Through the work of nurses, we also see how other caregivers outside the hospital became important members in the systems of care established by nurses and other healthcare professionals. Most children with pediatric AIDS were born with the disease — over 80 percent — which meant that their mother (and possibly father) also had the disease. This often meant that mothers and fathers had died or would die from the disease, or were otherwise too sick to care for their children. Orphaned HIV-positive children were thus cared for by foster families, foster-care facilities, and grandmothers. Adults with AIDS, especially towards the end of life, certainly required the assistance of others to care for them when the illness became worse. Children, on the other hand, required assistance from the time they were born and, most often, until they died. Many of the grandmothers and foster parents who became caregivers to children with pediatric AIDS, especially in cities like Newark, were older women of color. Though this was not the first time in U.S. history that women of color provided important, informal health care to members of their family and community, the history of pediatric AIDS allows to interrogate how those experiences may have differed in the age of AIDS.⁷

Pediatric AIDS was also not the first time a deadly or debilitating disease affected children. Histories like Gretchen Krueger's *Hope and Suffering: Children, Cancer, and*

York: Basic Books, 1987); Darlene Clark Hine, *Black Women in White : Racial Conflict and Cooperation in the Nursing Profession, 1890-1950* (Bloomington: Indiana University Press, 1989); Julie Fairman, *Critical Care Nursing : A History* (Philadelphia : University of Pennsylvania Press, 1998); Patricia D'Antonio, *American Nursing : A History of Knowledge, Authority, and the Meaning of Work* (Baltimore : Johns Hopkins University Press, 2010); Julie Fairman, *Making Room in the Clinic: Nurse Practitioners and the Evolution of Modern Health Care*, (New Brunswick: Rutgers University Press, 2008); Peggy McGarahan, *Transcending AIDS : Nurses and HIV Patients in New York City /* (Philadelphia : University of Pennsylvania Press, 1994.).

⁷ See, for example: Susan Smith, *Sick and Tired of Being Sick and Tired: Black Women's Health Activism in America, 1890-1950* (Philadelphia: University of Pennsylvania Press, 2010); Sharla M. Fett, *Working Cures : Healing, Health, and Power on Southern Slave Plantations* (Chapel Hill: University of North Carolina Press, 2002); Alondra Nelson, *Body and Soul : The Black Panther Party and the Fight against Medical Discrimination* (London: University of Minnesota Press, 2011).

the Paradox of Experimental Medicine (2008), and other scholarship on children's health, help situate the emergences of pediatric AIDS within the broader histories of childhood illness, death, and suffering. Most notably, sick, dying, and at-risk children garner a different type of public attention than adults, especially if they are dying from the same disease. Informed by the work of children's health historians, the history of AIDS, especially, compels us to interrogate what happens when disease associated with the taboo behavior of adults (especially their parents) sickens children.⁸

An important historical continuity illuminated by the history of pediatric AIDS, one that is underexplored in the AIDS literature, is how the cultural framing of children as "innocent victims" of disease factored in the nation's response to the AIDS epidemic. On the one hand, the HIV-positive children garnered outsized political and cultural attention in the late 1980s and early 1990s. Though children represented about two percent of all people with HIV-AIDS in the country, their innocent victim status helped propel them to

⁸ Sydney A. Halpern, *American Pediatrics : The Social Dynamics of Professionalism, 1880-1980* (Berkeley : University of California Press, 1988); Richard A. Meckel, *Save the Babies: American Public Health Reform and the Prevention of Infant Mortality, 1850-1929* (Ann Arbor: University of Michigan Press, 1990); Charles R. King, *Children's Health in America : A History* / (New York : Twayne Publishers, 1993); Brosco, Jeffrey P., "Policy and Poverty: Child and Community Health in Philadelphia, 1900-1930," *Archives of Pediatrics and Adolescent Medicine* 149 (December 1995); Evelyn Maxine Hammonds, *Childhood's Deadly Scourge: The Campaign to Control Diphtheria in New York City, 1880-1930* (Johns Hopkins University Press, 2002); Alexandra Stern and Howard Markel, eds., *Formative Years: Children's Health in the United States, 1880-2000* (Ann Arbor: University of Michigan Press, 2002); Janet Golden, Richard A. Meckel, and Heather Munro Prescott, *Children and Youth in Sickness and in Health: A Historical Handbook and Guide* (Greenwood Press, 2004); Janet Lynne Golden, *Message in a Bottle: The Making of Fetal Alcohol Syndrome* / (Cambridge, Mass. : Harvard University Press, 2005); Cynthia R. Comacchio, Janet Lynne Golden, and George Weisz, eds., *Healing the World's Children: Interdisciplinary Perspectives on Child Health in the Twentieth Century*, (Montréal, Québec: McGill-Queen's University Press, 2008); Cynthia A. Connolly, *Saving Sickly Children : The Tuberculosis Preventorium in American Life, 1909-1970* (New Brunswick, N.J.: Rutgers University Press, 2008); Gretchen Krueger, *Hope and Suffering: Children, Cancer, and the Paradox of Experimental Medicine* (Baltimore: Johns Hopkins University Press, 2008); Cynthia A. Connolly, *Children and Drug Safety Balancing Risk and Protection in Twentieth-Century America* / , n.d.; Meghan L. Crnic, "Seeking the Salubrious Sea : The Health and Environments of Urban American Families, 1870-1930" (PhD diss., University of Pennsylvania, 2013).

the top of the public agenda.⁹ In part, such public exposure helped policymakers and politicians argue for, and pass, one of the most significant pieces of AIDS-relief legislation in the U.S., the Ryan White CARE Act (1990). Their victimhood status, in part, also helped in the development of a techno-scientific intervention that would drastically reduce the overall numbers of children born with HIV.¹⁰

On the other hand, the innocent victimhood of children with AIDS was complicated by race and place. One of the few AIDS scholars that directly addressed the innocent victimhood of children and women of color was the political scientist and African American studies' scholar Cathy Cohen. Her book, *The Boundaries of Blackness: AIDS and the Breakdown of Black Politics* (1999), remains an important political and sociological analysis of how Black leaders responded to the AIDS crisis. Like a number of white politicians, some Black elected leaders often framed children with HIV-AIDS as “innocent victims.” They also cast HIV-positive women (if the disease was contracted through heterosexual sex, rather than IV drug use) as innocent victims as well. Cohen is critical of how the rhetoric of innocent victimhood, among some Black leaders, further marginalized gay men and IV drug users in Black communities.¹¹

More importantly, Cohen reminds us that not all “innocent victims” of AIDS were treated equally in the public discourse about, and in historical memory of, the epidemic. Though pediatric AIDS is not a critically analyzed in her work, Cohen’s scholarship is

⁹ I discuss the epidemiology of pediatric AIDS in chapter one.

¹⁰ Patricia D. Siplon, *AIDS and the Policy Struggle in the United States* (Washington, DC: Georgetown University Press, 2002).

¹¹ Cathy J. Cohen, *The Boundaries of Blackness : AIDS and the Breakdown of Black Politics* (Chicago: University of Chicago Press, 1999); Nancy Goldstein and Jennifer L. Manlowe, eds., *The Gender Politics of HIV/AIDS in Women: Perspectives on the Pandemic in the United States* (New York: New York University Press, 1997).

important in understanding how the cultural framing of children as “innocent victims” was complicated by race, especially as it related to how Americans responded to the epidemic. While children of color comprised the majority of those born with the disease, white children with hemophilia, such as Ryan White and the Ray brothers, remain the most recognizable child representatives with the disease. “It seems that even among ‘innocent victims,’” Cohen wrote, “patterns of marginalization that stratify along characteristics such as race, gender, class, and this case route of transmission, are actively at work.”¹²

But as we interrogate how and why pediatric AIDS became political visible in the late 1980s and early 1990s, we see how they also became “innocent victims” of “the inner city.” Drawing on histories of poverty and the “underclass” during the 1970s and 1980s, we discover how Americans saw children with HIV-AIDS as a byproduct of a “pathological” place. Here, my use of “the inner city” connotes the way Americans talked about, and perceived, poor urban neighborhoods. Though “ghetto” was still used by Americans to describe these neighborhoods, “the inner city” became the dominant phrase during the 1980s and 1990s. As the nation turned its attention to problems like the proliferation of crack-cocaine, increased violence, and entrenched poverty in some urban areas, children with HIV-AIDS would simultaneously be seen as innocent victims of AIDS *and* the poor urban environments in which they lived. This was not the first time Americans grew concerned about the problem of poverty and children’s health in the

¹² Cohen, *The Boundaries of Blackness*, 173; Information about Ryan White and other children with hemophilia that contracted HIV from contaminated blood products is derived from: Stephen G. Pemberton, *The Bleeding Disease: Hemophilia and the Unintended Consequences of Medical Progress* (Baltimore: John’s Hopkins University Press, 2011).

U.S., but particularities of how Americans understood urban poverty, and families of color living in poor urban environments, was profoundly shaped by a new poverty discourse that emerged after the 1960s.¹³

Informing that analysis, especially as it relates to the history of AIDS in the United States, is the work of Stephen Inrig, a historian of medicine. In *North Carolina and the Problem of AIDS: Advocacy, Politics and Race in the South* (2011), Inrig suggests that standard narratives about the epidemic, which largely focuses on HIV-AIDS among adult gay men in places like New York City and San Francisco, rendered invisible the problem HIV posed in places like North Carolina. A close reading of Inrig's work reveals that such traditional perceptions of the AIDS epidemic compels us to interrogate how and why images of AIDS are continually linked to images of white gay men in the urban North affected with AIDS. In this respect, his scholarship provides a useful way of thinking critically about the ways in which we can integrate histories of place in our analysis of the AIDS epidemic in America.¹⁴

Other historians have provided important insight into how to interrogate race and place, especially as it relates to the historiography of health care and public health. Two histories are particularly informative in this respect. The first is Keith Wailoo's *Dying in the City of the Blues: Sickle Cell Anemia and the Politics of Race and Health* (2001).

¹³ See, for example: Michael B. Katz, *The Undeserving Poor: From the War on Poverty to the War on Welfare* (New York: Pantheon Books, 1989); Michael B. Katz, *Why Don't American Cities Burn?*, 1st ed. (Philadelphia: University of Pennsylvania Press, 2011); Caroline Jean Acker, "How Crack Found a Niche in the American Ghetto: The Historical Epidemiology of Drug-Related Harm," *BioSocieties* 5, no. 1 (March 2010): 70–88; David R. Farber, *Crack: Rock Cocaine, Street Capitalism, and the Decade of Greed* (New York: Cambridge University Press, 2019). Julilly Kohler-Hausmann, *Getting Tough: Welfare and Imprisonment in 1970s America* (Princeton: Princeton University Press, 2017).

¹⁴ Stephen Inrig, *North Carolina & the Problem of AIDS: Advocacy, Politics, & Race in the South* (Chapel Hill: University of North Carolina Press, 2011).

Wailoo's work has influenced the ways in which historians have engaged the politics of race and healthcare in American history. But his work is also informative for thinking about how to integrate urban histories into our historical understanding about disease, healthcare, and suffering. In his book, the city of Memphis is more than a backdrop for his story about the politics of race and sickle cell disease; it is an important character in his history. When considering the history of pediatric AIDS, we see a similar phenomenon. Pediatric AIDS was largely found in poor urban environments, and although three cities became the epicenter of the outbreak, Newark would emerge as an important character in history of pediatric AIDS.¹⁵

The second model is Samuel K Roberts Jr.'s *Infectious Fear: Politics, Disease, and the Health Effects of Segregation* (2009). Roberts reveals the deleterious health effects of racialized segregation. He shows that the physical, social, and racialized landscapes of early-twentieth-century Baltimore helped produce the disproportionate rates of tuberculosis among African Americans.¹⁶ Taken together, both histories suggest that stories about urban spaces and places are integral in our understanding of race, illness, healthcare, and suffering when considering the history of pediatric AIDS. Using Roberts specifically, we also see how post-World War II racialized segregation became an important factor for where and why pediatric AIDS developed in some cities.

American historians have recently begun to engage the history of HIV-AIDS as it relates to change in the country since the 1960s, but pediatric AIDS remains absent.

¹⁵ Keith Wailoo, *Dying in the City of the Blues : Sickle Cell Anemia and the Politics of Race and Health* (Chapel Hill, NC: University of North Carolina Press, 2001).

¹⁶ Samuel Roberts Jr., *Infectious Fear : Politics, Disease, and the Health Effects of Segregation* (Chapel Hill: University of North Carolina Press, 2009); David McBride, *From TB to AIDS: Epidemics among Urban Blacks since 1900* (SUNY Press, 1991).

These historians show how HIV-AIDS intersects with important themes in American history such as, race, politics, poverty, gender, and sexuality. One of the first historians to fully engage with the intersecting historiographies of both U.S. history and HIV-AIDS is Jennifer Brier. In her book *Infectious Ideas: U.S. Political Responses to the AIDS Crisis* (2009), Brier shows how HIV became an important disruption for AIDS activist organizations, political allies in the Regan Administration, foreign policymakers, and large global philanthropic organizations like the Ford Foundation. Building on the work of Brier and others, the history of pediatric AIDS engages with similar themes and topics in U.S. history and urban history.¹⁷ They include, for example, urban renewal, segregation, and race. Most importantly, the history of pediatric AIDS adds a critical perspective that American historians could use to interrogate how themes like age factored in the country's response to urban poverty in the 1980s and 1990s, especially the rise of the "underclass."¹⁸

¹⁷ Jennifer Brier, *Infectious Ideas: U.S. Political Responses to the AIDS Crisis* (Chapel Hill: The University of North Carolina Press, 2011); In addition to engaging with the historiography about poverty in the late-twentieth century United States, this dissertation seeks to engage with urban historians. See, for example: Samuel Zipp, *Manhattan Projects the Rise and Fall of Urban Renewal in Cold War New York* (New York: Oxford University Press, 2010); Thomas J. Sugrue, *The Origins of the Urban Crisis: Race and Inequality in Postwar Detroit: With a New Preface by the Author*, 1st Princeton Classic ed. (Princeton: Princeton University Press, 2005); Arnold R. Hirsch, *Making the Second Ghetto: Race and Housing in Chicago 1940-1960* (Chicago: University of Chicago Press, 1998); Kenneth L. Kusmer and Joe W. Trotter eds., *African American Urban History since World War II* (Chicago: University of Chicago Press, 2009); Alejandro Portes, *City on the Edge: The Transformation of Miami* / (Berkeley: University of California Press, 1994); Julia Rabig, *The Fixers: Devolution, Development, and Civil Society in Newark, 1960-1990*, 2016; N. D. B. Connolly, *A World More Concrete: Real Estate and the Remaking of Jim Crow South Florida*, 2014; Mark Krasovic, *The Newark Frontier: Community Action in the Great Society*, 2016; Lizabeth Cohen, *A Consumers' Republic: The Politics of Mass Consumption in Postwar America*, 1st ed (New York: Knopf: Distributed by Random House, 2003).

¹⁸ Interchange "HIV/AIDS and U.S. History," *Journal of American History* 104, no. 2 (September 1, 2017): 431-60. This forum, which Brier helped organize, represents recent enthusiasm among American historians that engage with the history and historiography of HIV-AIDS as it relates to major themes in U.S. history. Absent from the discussion was how HIV-AIDS affected children and their families.

Lastly, when we consider the emergence and prevalence of pediatric AIDS in urban America, its particular geographic distribution compels us to use analytical frameworks deployed by environmental historians. The geography of HIV-AIDS among adults was certainly concentrated in cities, but not exclusively. Pediatric AIDS, on the other hand, was much more concentrated in urban areas, and specifically certain cities and certain neighborhoods in those cities. In the three decades following the Second World War, just as hundreds of thousands of African Americans were migrating out of the South, many U.S. cities experienced the loss of manufacturing jobs, disinvestment, racist zoning policies, disruptive urban renewal initiatives, concentrated poverty, and an increase in racialized segregation. This helped create a particular ecology in which HIV thrived, but it also helped create the social and physical environments that constrained pediatric AIDS in specific places. While sociologists and anthropologists have helped us understand the structural forces — or the “structural violence” — that has led to racialized and geographic health disparities, environmental history methods provide a useful set of tools for interrogating how and why these urban environments formed, and how people interact with those same environments.¹⁹ This is crucial in understanding the geography and epidemiology of pediatric AIDS, especially when considering its close ties to the landscape of heroin use in the U.S. during the late 1970s and early 1980s.

¹⁹ This is informed by the following environmental histories and scholars: Gregg Mitman, *Breathing Space: How Allergies Shape Our Lives and Landscapes* (New Haven: Yale University Press, 2007); Andrew Hurley, *Environmental Inequalities: Class, Race, and Industrial Pollution in Gary, Indiana, 1945-1980* (Chapel Hill: University of North Carolina Press, 1995); Andrew Hurley, ed., *Common Fields: An Environmental History of St. Louis* (St. Louis: Missouri Historical Society Press, 1997); Dawn Day Biehler, *Pests in the City: Flies, Bedbugs, Cockroaches, and Rats* (University of Washington Press, 2013); Linda Lorraine Nash, *Inescapable Ecologies: A History of Environment, Disease, and Knowledge* (Berkeley: University of California Press, 2006).

The chapters that follow track the rise and decline of pediatric AIDS in the United States. The history begins around 1950, when changes in U.S. cities created the ecological niche in which HIV would eventually thrive by the late 1970s. The story ends during the second decade of the twenty-first century, when the nation saw some of the lowest rates of pediatric AIDS since the epidemic began. The dissertation's central theme of place ties the chapters together, and each chapter presents a micro-history of five interrelated episodes that comprise the whole of the history of pediatric AIDS in the United States. The often overlapping chronologies of each chapter reflect a particular subsidiary theme or topic that structures each of the discrete episode.²⁰

The first of these episodes explores how pediatric AIDS became concentrated in particular urban environments. In order to understand this concertation, chapter one first provides a historical epidemiology and geography of pediatric AIDS in the United States. Relying on local and national AIDS surveillance data, the first part of this chapter maps how pediatric AIDS became especially concentrated along the East Coast. Using that same information, we narrow in on two specific areas of the country that saw the highest numbers HIV-AIDS among children: the Newark-New York City and Miami, Florida metropolitan areas. The social, economic, and physical changes that occurred in American cities from 1950 to 1980 helped contribute to the particular geographic distribution of pediatric AIDS in the U.S. This chapter shows how pediatric AIDS was most prominent in cities, and areas of cities, that had high rates of IV drug use, which was the result of concentrated poverty and racialized segregation. But those factors alone

²⁰ The organization of the dissertation is informed by Brier, *Infectious Ideas*.

cannot explain why pediatric AIDS was concentrated in some cities, while others were largely spared. I argue, therefore, that the disease became an environmental hazard for some children of color and their families, and not others.

Those cities became the epicenters for the outbreak of pediatric AIDS in the United States, and the places where healthcare workers responded to the disease. Chapter two begins with a brief overview, for context, about the history of children's health and health care in the United States from the 1950s to the late 1960s. Using the pediatrician Dr. James Oleske as our guide, the chapter explores how pediatric AIDS was first identified, how that identification was shrouded in scientific controversy, how healthcare workers developed models of pediatric AIDS care, and who would emerge as important pediatric-AIDS advocates. Moreover, when considering Oleske, specifically, we see how events and people in Newark, after the violent uprising of 1967, shaped his career as a pediatric-AIDS advocate. In this respect, Oleske differed from the other pediatric-AIDS representatives that would emerge before and after 1985. But rather than provide a biographical sketch of one physician, I use Oleske to argue that pediatric-AIDS advocates became effective and powerful spokespeople for children and families with HIV-AIDS because of who they were not: residents of the poor, urban communities of color in which they worked.

Between 1985 and 1987, pediatric AIDS gained some cultural visibility. But by 1987, pediatric AIDS would gain a greater degree of national attention. In chapter three, I show how the "innocent victim" narrative that was used to raise awareness of pediatric AIDS merged with a new poverty discourse dominated by discussions about the "underclass." The chapter begins with a history of that poverty discourse and how

particular depictions of American “inner cities” became linked to the way Americans understood urban poverty in the 1980s. The rest of the chapter describes how pediatric AIDS gained a heightened degree of political and cultural visibility between 1986 and 1992, after which children with AIDS faded from the public’s attention. It was during those years that HIV-AIDS among families of color became a “family disease.” I show that the emergence of the family-disease narrative represents an important phenomenon in the history of pediatric AIDS. I argue the rise of the family-disease discourse reveals how the social and geographic imaginaries that structured the way Americans understood poor urban areas — as a foreign territory within the borders of the nation — ultimately made pediatric AIDS into just another problem of “the inner city.” In the end, the family-disease framing of AIDS was short-lived and relegated to the margins of the larger, evolving public discourse about the epidemic during these years.

Though the family-disease framing never gained political potency, healthcare workers nonetheless well understood that AIDS was a family disease among some urban families of color. Chapter four explores the work of nurses and other who cared for children with HIV-AIDS in the years before effective antiretroviral therapies. Here, I provide a fine-grained analysis of how the pediatric-AIDS system of care was established, operated and maintained. Nurses — along with other caregivers outside the hospital, especially foster families and grandmothers — were critical actors in the operation and maintenance of that system. One nurse practitioner in particular, Mary Boland, emerges as an especially important figure. In helping to create the model of pediatric AIDS care used in Newark, Boland, and the Children’s Hospital AIDS Program (CHAP), became nationally and internationally recognized for their work. Most

importantly, I argue, nursing provides us an important vantage point from which to shift our historical perspective about the introduction of effective antiretroviral medications. While those drugs became important, lifesaving medications, any historical emphasis on the development of those medications transforms effective HIV-AIDS therapeutics into supplanting technologies that rendered what came before them as merely “health care in the meantime.”

The use of antiretroviral medications was an important development in the prevention of pediatric AIDS. In the final chapter, I follow the decline in perinatally transmitted HIV through the work of AIDS prevention advocates, public health experts, and healthcare professionals as they tried to prevent HIV transmission in unborn children. The chapter pivots on the AIDS Clinical Trial Group study, 076. The clinical trial was initiated to see if AZT could reduce perinatal transmission of HIV. Before the trial started in 1991, efforts to prevent pediatric AIDS centered on preventing women from contracting the disease or encouraging HIV-positive women to delay pregnancy. In this context, women’s-health advocates emerged as important actors in pediatric-AIDS prevention efforts. Meanwhile, starting in 1985, HIV-AIDS harm-reduction specialists promoted the safe use and distribution of sterile syringes as a means of preventing HIV in families of color – until 1994. Then, the 076 trial proved that AZT was effective in reducing the perinatal transmission of HIV.

Over the next several years, the drug proved to be the most effective means of preventing pediatric AIDS. But as this chapter suggests, we cannot fully understand the broader landscape of pediatric AIDS prevention without considering the work of women’s-health and harm-reduction advocates. In the end, AZT would drastically drive

down rates of perinatal transmission, yet the medication must be understood within the larger context of the burdens of prevention caused and exacerbated by the social and environmental conditions which structured the lives of some families of color. Here, I argue, that the development and success of AZT was a specific, techno-scientific response to the nation's failures to adequately address HIV-AIDS in poor urban environments. AZT reduced the risk of HIV infection among children, but many women of color remained vulnerable to the disease.

This story of pediatric AIDS will advance our understanding about the epidemic's history in the United States. This dissertation analyzes the intersections of race, place, politics, poverty, and illness at the end of the twentieth century. Most importantly, this story compels us to confront the humanity of those marginalized children who lived with and died from AIDS.

CHAPTER 1: THRIVING IN THE CITY: ENVIRONMENTAL INEQUALITIES AND THE ROOTS OF PEDIATRIC AIDS, 1950—1987

Toni was born with HIV-AIDS in 1978. Born in New York City at Babies Hospital, her patient record indicates little about the child's early years with the disease. Nor was there much known about her family. In 1983, her record indicated that "[a]ll we know is that her mother is a drug addict and that her father died of bacterial endocarditis" – the latter was a condition common among intravenous (IV) drug users. Toni, like the majority of children with HIV-AIDS in the United States, acquired the disease from her mother.²¹

The date and place of Toni's birth are important when considering the roots of pediatric AIDS in the United States. The first documented case of pediatric AIDS occurred in 1977 in New York City. That city, along with Newark, New Jersey and Miami, Florida, represented the three epicenters for pediatric AIDS in the country. As the epidemic grew and spread through the U.S., more states and cities would record cases of pediatric AIDS. But nowhere else in the United States would see as many cases of pediatric AIDS as did the Newark-New York metropolitan area and the Interstate 95 (I-95) corridor between Miami and West Palm Beach.

²¹ Letter from Dr. Jashed F. Kanga to Dr. George Stern, Tulane Medical Center, April 15, 1983, "Toni" patient record, Dr. James Oleske Personal Papers (hereafter cited; Oleske Personal Papers). Toni is a pseudonym. All of the children's names used in the dissertation, unless otherwise noted, are not the actual names of the children. This is due to the fact that information drawn from patient records, in particular, has been deidentified. I thus provide names based on the reported sex of the child. I also received an IRB exemption for the use of these materials.

The reference to drug addicts, as seen in Toni's patient record, was not uncommon among health care professionals. While some may have held moralistic judgments about a parent's or parents' use of drugs, references to "drug addicts" was often used by those health care workers who were also sympathetic to the plight of their patient's parents. We also see the use of "IV drug user" in the historical record during the 1980s and 1990s as some health care workers, and others, moved away from using potentially problematic language such as "addict." Unless quoting a historical actor, I will use intravenous (IV) drug user to describe those that used or were purported to have used drugs intravenously.

This chapter thus explores the regional and local distribution of pediatric AIDS in the United States, particularly how it was concentrated in certain areas. Of course, there were regional differences in the distribution of HIV-AIDS among adults as well. When considering the cumulative numbers and rates of cases reported to the Centers for Disease Control and Prevention (CDC), higher numbers of HIV-AIDS were found in large U.S. cities. This does not suggest that epidemic among adults was *only* a problem in urban areas — it was not. Adults in other areas of the country were affected by the disease.²² But the concentration of pediatric AIDS reveals a striking feature about the distribution of the disease among children and their families: the stark geographic disparities of the epidemic in children. This chapter shows how social, economic and physical changes to some American cities between 1950 and 1980 helped contribute to the particular geography of pediatric AIDS. Most notably, cities and neighborhoods that witnessed high rates of IV drug use during the late-1970s and early-to-mid 1980s also saw higher incidences of pediatric AIDS. Nowhere was this more pronounced than in northeastern New Jersey and New York City. But the mere presence of IV drug use alone cannot explain why that region of the country experienced such a concentration of pediatric AIDS. Near the peak of the epidemic in children during the 1990s, Margaret J. Oxtoby, physician and epidemiologist at the CDC, wrote about those regional disparities as they related to IV drug use. In New York and northern New Jersey nearly 50 percent of drug

²² Cumulative rates of adult cases are drawn from, Center for Disease Control and Prevention (CDC) *HIV/AIDS Surveillance Report*, “U.S. HIV and AIDS cases reported through December 1994,” Year-end Edition Vol. 6, No. 2. For accounts of HIV-AIDS in adults outside the urban north and U.S. cities, see, for example: Inrig, *North Carolina & the Problem of AIDS*; Abraham Verghese, *My Own Country : A Doctor’s Story*, 1st Vintage books ed. (New York : Vintage Books, 1995).

users tested positive for HIV. “While IV drug use is also common in other cities,” she wrote, “HIV...rates in drug users outside the Northeast average around 5 [percent].”

Though regional disparities are an important part of the history of pediatric AIDS, the stark geographical contrast is particularly revealing at the local level. Here, New York City stands out above all other places. Since the beginning of the epidemic, New York recorded the highest numbers of pediatric AIDS cases in the United States. But even within the five boroughs of New York, pediatric AIDS remained relegated to specific areas of the city, which became evident by 1987. [Figures 1 and 2].²³

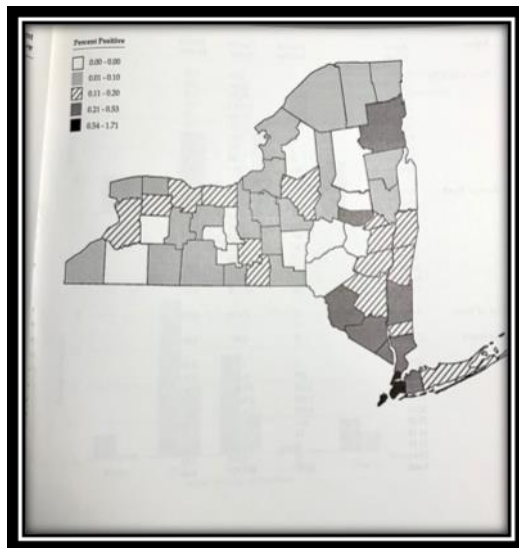


Figure 1: AIDS in New York State, 1993

The black section at the bottom of the New York State map is New York City
 Source: New York State Department of Health, AIDS in New York State, 1993

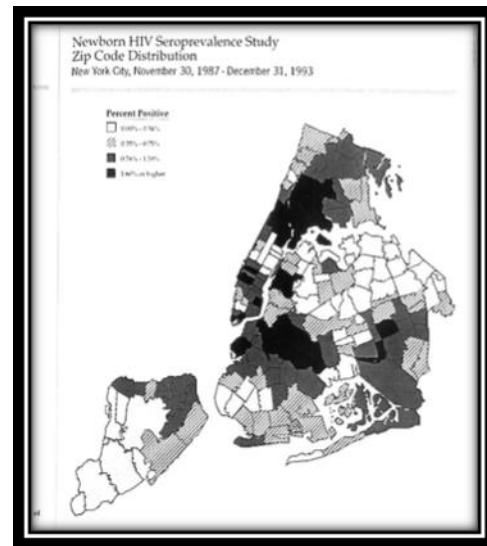


Figure 2: Pediatric AIDS in New York City, 1987-1993

The dark areas represent the highest rates of pediatric AIDS in the city. The South Bronx, East Harlem, Harlem, and parts of Brooklyn represent the areas of concentration
 Source: New York State Department of Health, AIDS in New York State, 1993.

The local distribution of pediatric AIDS also reveals how the disease was grafted onto the geographies of race and class in New York and elsewhere. When looking at the

²³ Lukas Engelmann, *Mapping AIDS: Visual Histories of an Enduring Epidemic* (New York: Cambridge University Press, 2018).

patterns of pediatric AIDS in the U.S., the three epicenters represent how closely linked the disease was to historical patterns of racialized segregation and the concentration of poverty in communities of color, which especially occurred after the end of World War II. Those links, of course, were not unique to pediatric AIDS; other diseases are often associated with poverty and racialized segregation, which included adults as well.²⁴

Most importantly, children with HIV-AIDS acquired the disease from their mother in utero, but how the mother contracted HIV was complicated. We know that structural inequities — such as poverty, racism, and sexism — can constrain the agency of men and women alike. Being forced to survive under circumstances where there is little control over one's present and future, has often resulted in negative health outcomes, which included HIV-AIDS.²⁵ Some have argued that the built environment, specifically cities, can also determine the health outcomes of populations. Combined with the structural forces that can constrain the agency of individuals, sociologists have shown how space can have a similar effect.²⁶ Most notably, however, environmental historians have provided some of the most useful frameworks for understanding the structural *and*

²⁴ This is especially informed by the work of the following two historians: Roberts, *Infectious Fear*; McBride, *From TB to AIDS*.

²⁵ Paul Farmer, Margaret M Connors, and Janie Simmons, *Women, Poverty and AIDS: Sex, Drugs, and Structural Violence*, 2nd ed. (Monroe, Me. : Common Courage Press, 2011); Paul Farmer, *Infections and Inequalities: The Modern Plagues* (Berkeley: University of California Press, 1999). In the latter, Farmer expands upon ideas about how social inequalities create disparities in health outcomes. With respect to how HIV-AIDS disproportionately affect people of color living in poverty, Farmer tersely explains: "[d]espite the message of public health slogans -- 'AIDS is for Everyone' -- some groups are at high risk of HIV infection, whereas others clearly are shielded from risk." (51) For Farmer, the most "well-demonstrated" phenomena for understanding the unequal distribution of HIV-AIDS are the "*social inequalities* (emphasis original), which structure not only the contours of the AIDS pandemic but also the nature of outcomes once an individual is sick with complications of HIV infection." (51-52) This is also informed by: Eric Klinenberg, *Heat Wave: A Social Autopsy of Disaster in Chicago* (Chicago: University of Chicago Press, 2002); Philippe I. Bourgois, *In Search of Respect : Selling Crack in El Barrio*, 2nd ed. (New York: Cambridge University Press, 2003).

²⁶ See, for example: Kevin Fitzpatrick, *Unhealthy Cities : Poverty, Race, and Place in America*, 2nd ed. (New York: Routledge, 2011).

historical processes that have created, what Gregg Mitman calls, “ecolog[ies] of injustice,” particularly for communities of color. They help us understand how and why the formation of certain ecologies have factored into the unequal distribution of HIV-AIDS among mothers-to-be and their children.²⁷ Though children born with HIV-AIDS were more likely to be Black, Latinx, and living in a poor urban environment, not every place that experienced racialized segregation and concentrated poverty also had high rates and cases of HIV-AIDS among children. When considering the ecological particularities that led to the unequal distribution of pediatric AIDS, we see how the disease became an environmental hazard for some poor children and families of color, and not others.

Towards a Historical Epidemiology and Geography of Pediatric AIDS

Given the unequal distribution of pediatric AIDS, the historical epidemiology and geography of the disease provides a useful starting point for understanding the ecological particularities that gave rise to the concentrated cases of the disease among children and their families. Since the CDC began publishing HIV-AIDS data in 1984, Black and Latinx children dominated the number of pediatric AIDS cases in the U.S. While the numbers of pediatric AIDS would drastically decline in the late 1990s, the racial and ethnic disparities remained relatively constant from 1984 through much of the first decade-and-half of the twenty-first century [Figure 3]. Between 1985 and 2017, the

²⁷ Mitman, *Breathing Space*; Biehler, *Pests in the City*; Andrew Hurley, “Floods, Rats, and Toxic Waste: Allocating Environmental Hazards Since World War II”, *Common Fields*.

largest percentage of children with HIV-AIDS were Black or Latinx (roughly 80-85 percent of cases reported to the CDC).²⁸

The states that saw the first cases and the highest numbers of pediatric AIDS — Florida, New Jersey, and New York — saw some of the starkest racial disparities in the country. Locally, the percentage of Black and Latinx children with the disease was quite striking. In 2018, for example, 95 percent of children with HIV-AIDS in New York City were Black or Latinx.²⁹ The consistency, and in some cases growth of, the racial-ethnic disparities among children were also starkly different than those seen in adults. Though the demographics of new cases of HIV-AIDS began to shift towards Black and Latinx adults in the late 1980s and early 1990s, no such shift occurred among children who acquired the disease.³⁰

²⁸ Center for Disease Control (CDC), Acquired Immunodeficiency Syndrome (AIDS) Weekly Surveillance Report, December 31, 1984 (hereafter cited; CDC AIDS report, 1984). The graph in figure 1 is derived from: CDC, National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention Division of HIV/AIDS Prevention, “Pediatric HIV Surveillance,” accessed April 1, 2020, <https://www.cdc.gov/hiv/pdf/library/slidesets/cdc-hiv-surveillance-pediatric.pdf>. Though the graph from the CDC specifically showed cases of stage 3 AIDS, the graphic nonetheless visually captures the ways in which pediatric AIDS remained a problem among communities of color.

²⁹ A note on the use of language: Unless quoted, I use Black, African-American, Latinx, family/families of color to describe the children and families most affected by the epidemic – specifically Black, Latinx, and in some cases families of Haitian-descent. I am aware of, and sensitive towards, the fact that some of the actors I discuss in the dissertation may not have self-identified by the racial or ethnic categories used to describe them. The historical record, on the other hand, reveals a diverse use of racial and ethnic categories ranging from black and African American to Hispanic and Latino. I chose, instead, to use more contemporary language to describe the actors in my study as to avoid dated usage of certain terms – such as Hispanic.

³⁰ For New York City, see: New York City Department of Health and Mental Hygiene, HIV Epidemiology Program, “Perinatal HIV Among Children in New York City, 2018, published December 2019, accessed April 1, 2020, <https://www1.nyc.gov/assets/doh/downloads/pdf/dires/hiv-aids-in-pediatrics.pdf> For Miami-Dade County, see: Florida Department of Health in Miami-Dade County, HIV/AIDS Surveillance, “Monthly HIV/AIDS Surveillance Report” published, June 2016, accessed April 1, 2020, http://miamidade.floridahealth.gov/programs-and-services/infectious-disease-services/hiv-aids-services/_documents/hiv-surveillance-monthly-report-2016-06-B.pdf. For New Jersey, see: New Jersey Department of Health, Division of HIV, STD and TB Services, “New Jersey HIV/AIDS Report, June 30, 2015, accessed April 1, 2020, <https://www.nj.gov/health/hivstdtb/documents/newsletter/semi0615.pdf>. For a discussion about the changing demographics of HIV-AIDS in the U.S., see chapter three.

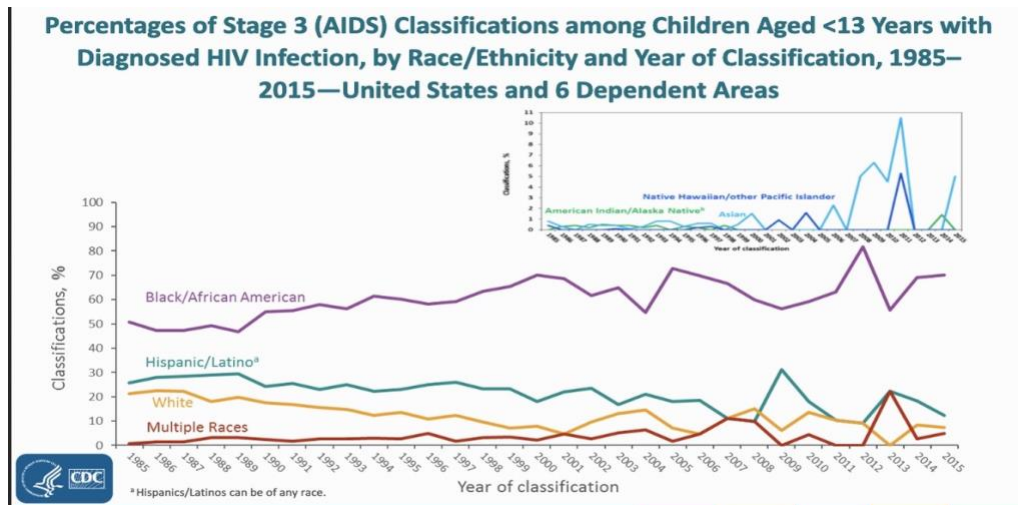


Figure 3: Disparities of Pediatric AIDS Cases by Race, 1985-2015

Source: National Centers for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention Division of HIV/AIDS Prevention, “Pediatric HIV Surveillance,” 2015

The majority of children with HIV-AIDS in the U.S. also acquired the disease in utero. Though the two most common ways children acquired the disease was through tainted blood or blood products and perinatal transmission, the latter was the most dominant. After 1985, blood products and donors were screened for HIV, and heat treatments of blood products, such as clotting factor, led to a drastic decrease in blood-borne cases in children. Regardless, roughly ten percent of all pediatric AIDS cases — before and after 1985 — were the result of blood transfusions and blood products. Some 90 percent of children with HIV-AIDS acquired it perinatally. White children also contracted the disease perinatally, but the vast majority of children born with HIV-AIDS were Black and Latinx. [Figure 4].³¹

³¹ Martha F. Rogers, et al, “Acquired Immunodeficiency Syndrome in Children: Report of the Centers for Disease Control National Surveillance, 1982 – 1985,” *Pediatrics*, 79. no. 6, (June 1987) 1008-104. Warren A. Andiman and John F. Modlin, “Vertical Transmission,” in Pizzo and Wilfert, *Pediatric AIDS*; Martha F. Rogers, “Pediatric HIV Infection in the United States,” in Philip A. Pizzo and Catherine M. Wilfert, eds., *Pediatric AIDS: The Challenge of HIV Infection in Infants, Children, and Adolescents*, 3rd ed (Baltimore:

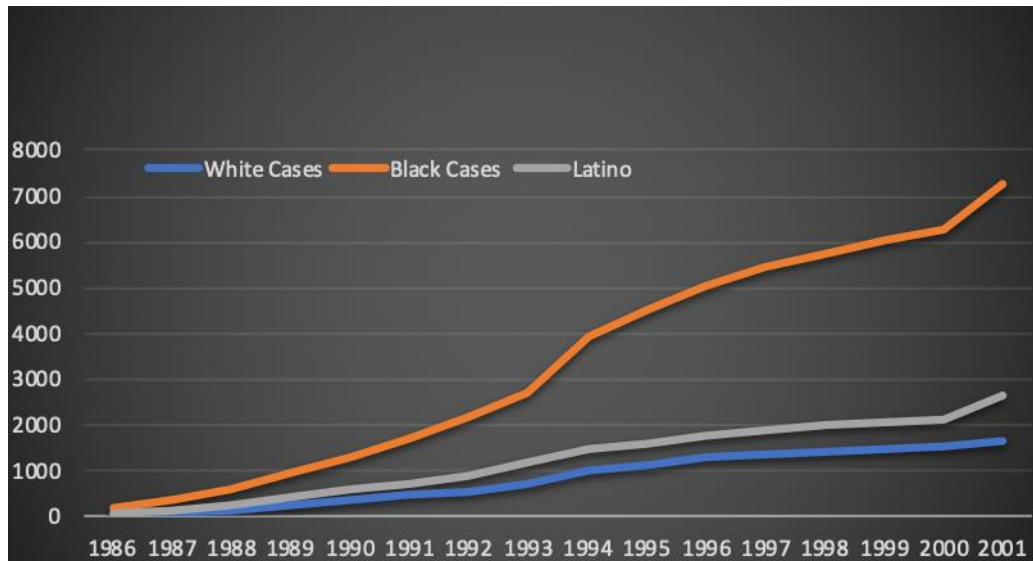


Figure 4: Cumulative Cases of Pediatric AIDS by Race, 1986-2001
 Source, CDC AIDS Surveillance Reports 1986 – 2001³²

Besides racial-ethnic disparities, the story of pediatric AIDS is also one of unequal geographic distribution. From 1984 to 2018, the CDC reported that every state, the District of Columbia, and three U.S. territories had recorded at least one case of pediatric AIDS. But those numbers varied from one reported case in the Northern Mariana Islands to the nearly twenty-five hundred in New York. Moreover, when considering states and territories with the highest numbers, only sixteen states, the District of Columbia, and Puerto Rico recorded cases exceeding one hundred. With the exception of California, Puerto Rico, Texas, and Illinois, the majority of states with more

Williams & Wilkins, 1998). For information about the HIV-AIDS and the blood supply see: Eric A. Feldman and Ronald Bayer, *Blood Feuds*; Pemberton, *The Bleeding Disease*, 237-283.

³² CDC, “AIDS Weekly Surveillance Report, December, 1986” to CDC, “U.S HIV and AIDS cases reported through December 2001,” *HIV/AIDS Surveillance Report*, Year-End edition, 13, no. 2. Before 1986, the CDC did report racial demographics for children that acquired the disease perinatally. I choose 2001 as the end year because the trends were relatively the same up to 2018. Also, when a number of surveillance reports are covered, I will cite the range as to save space. All of the cumulative numbers represented are not adjusted for changes that appear in the following year’s CDC Surveillance Report. The representations of these data are to illustrate the disparities between regions (states) and cities/metropolitan areas, rather than to show exact number of cases. The full list of the CDC Surveillance Reports can be found in the bibliography.

than one hundred cases were along the I-95 corridor on the east coast of the United States. In fact, by 2018, 77 percent of cumulative cases reported since 1984 came from those states alone, and when considering the states between Massachusetts and the District of Columbia (and the surrounding Washington DC region) those areas accounted for just over 50 percent of all states reporting more than one-hundred cases [Figures 5 and 6 show spread of pediatric AIDS by State with 100 or more cases].



Figure 5: States with Highest Reported Cases of Pediatric AIDS, 1984
Source: CDC Surveillance AIDS Report, December, 31 1984



Figure 6: States with the Highest Reported Cases of Pediatric AIDS, 2018
Figure 6: CDC HIV Surveillance Report, Vol 30, 2018

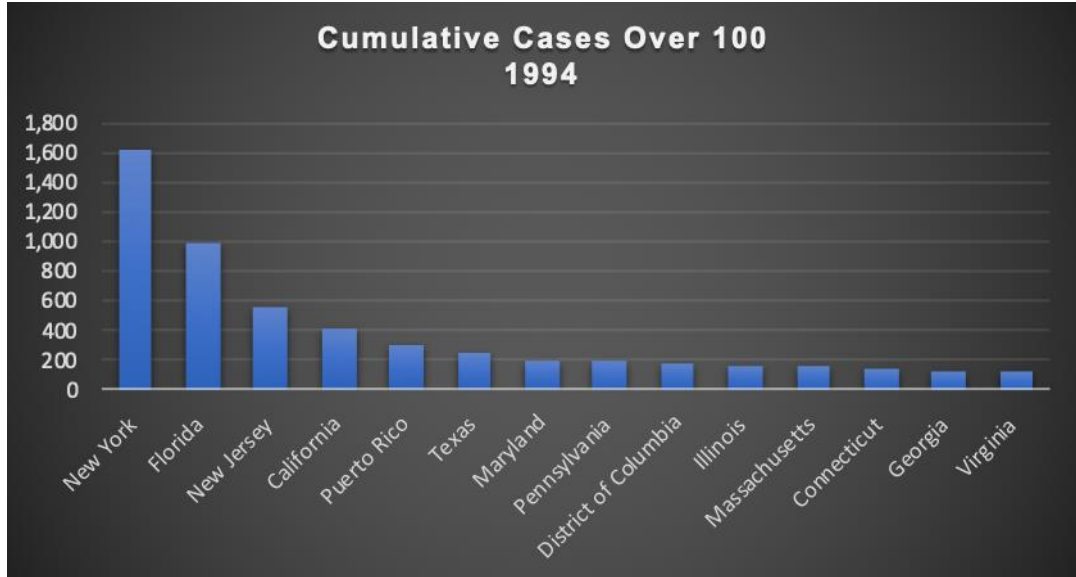


Figure 7: U.S. States with Cumulative Cases of Pediatric AIDS Over 100, 1994
 Source: CDC HIV/AIDS Surveillance Report, Year-End Edition, Vol 6, No 2, December 1994

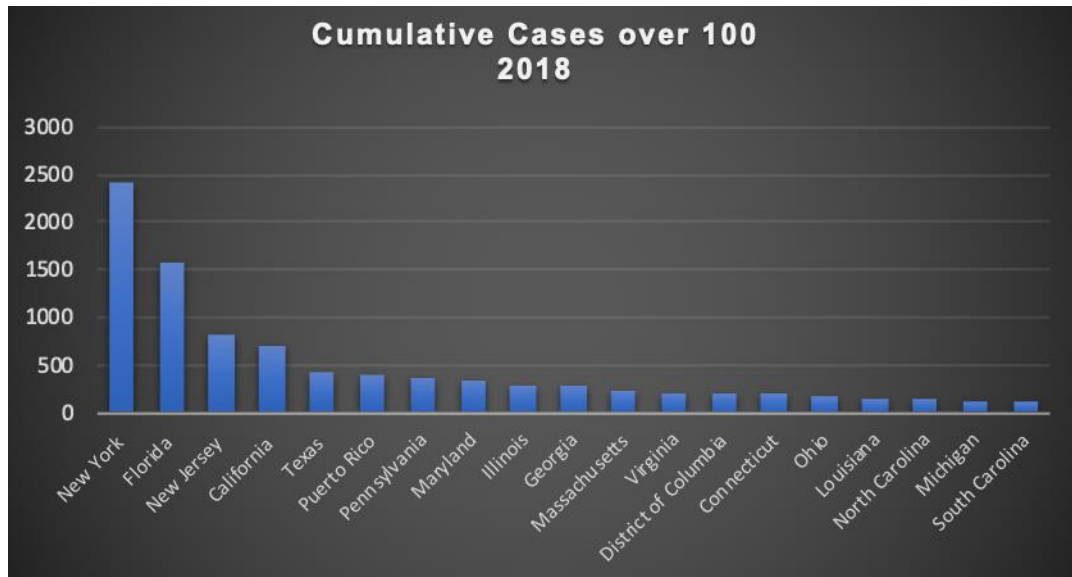


Figure 8: U.S. States with Cumulative Cases of Pediatric AIDS Over 100, 2018
 Source: CDC HIV Surveillance Report, Vol 30, 2018

Those regional disparities were further felt at the city level.³³ While adult HIV-AIDS was not relegated to urban areas, pediatric AIDS was overrepresented in a number of U.S. cities and metropolitan regions. As seen in adults, HIV-AIDS in children appeared in cities large and small. By 2018, cities diverse in size and population, such as New York City and Ogden, Utah — a city of around eighty-seven thousand people and roughly forty miles north of Salt Lake City, which has reported four cases since the beginning of the epidemic — had recorded cases of pediatric AIDS. Only one urban region, Boise, Idaho, had not recorded a single case of pediatric AIDS by 2018. Small-to-medium cities and metropolitan regions aside, the vast majority of pediatric AIDS cases were found in larger cities, with roughly 85 percent of children with HIV-AIDS residing in cities and metropolitan regions with populations above five hundred thousand people. [Figures 9 and 10].³⁴

³³ CDC, "AIDS Report, 1984" to CDC, "Diagnoses of HIV Infection in the United States and Dependent Areas, 2018," *HIV Surveillance Report*, Vol 30, 2018.

³⁴ CDC, *HIV Surveillance Report*, Vol 30, 2018. The cities and urban areas noted here are only the ones that the CDC reported based on their reporting categories. The total population of Ogden, Utah is derived from: United States Census Bureau, "Quick Facts, Ogden City, Utah," accessed April 1, 2020, <https://www.census.gov/quickfacts/ogdencityutah>.

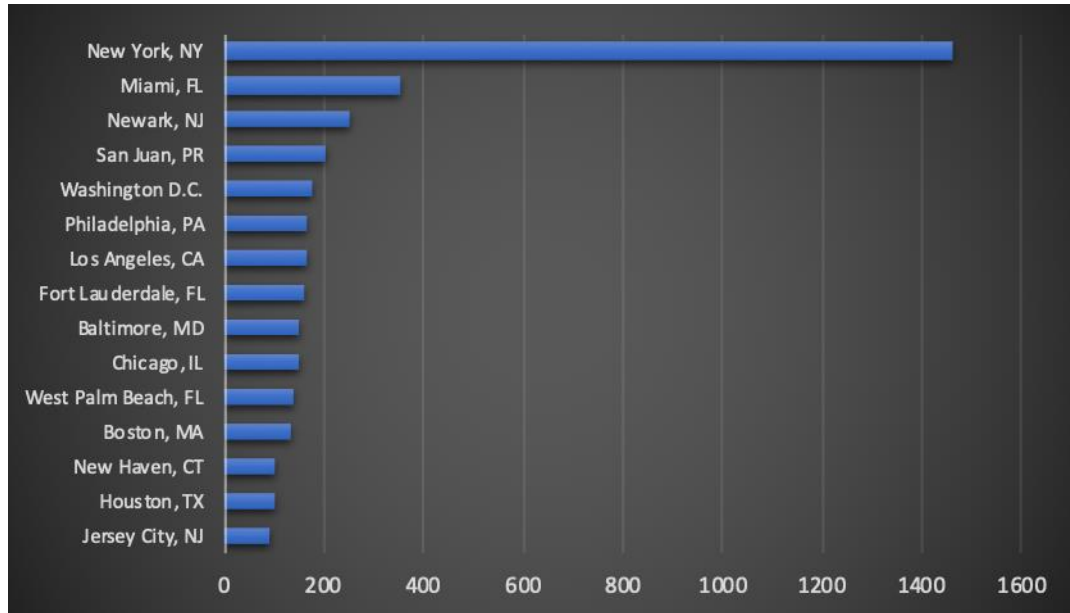


Figure 9: U.S. Cities with Pediatric AIDS Cases Over 90, 1994
 Source: CDC HIV/AIDS Surveillance Report, Year-End Edition, Vol 6, No 2, December 1994

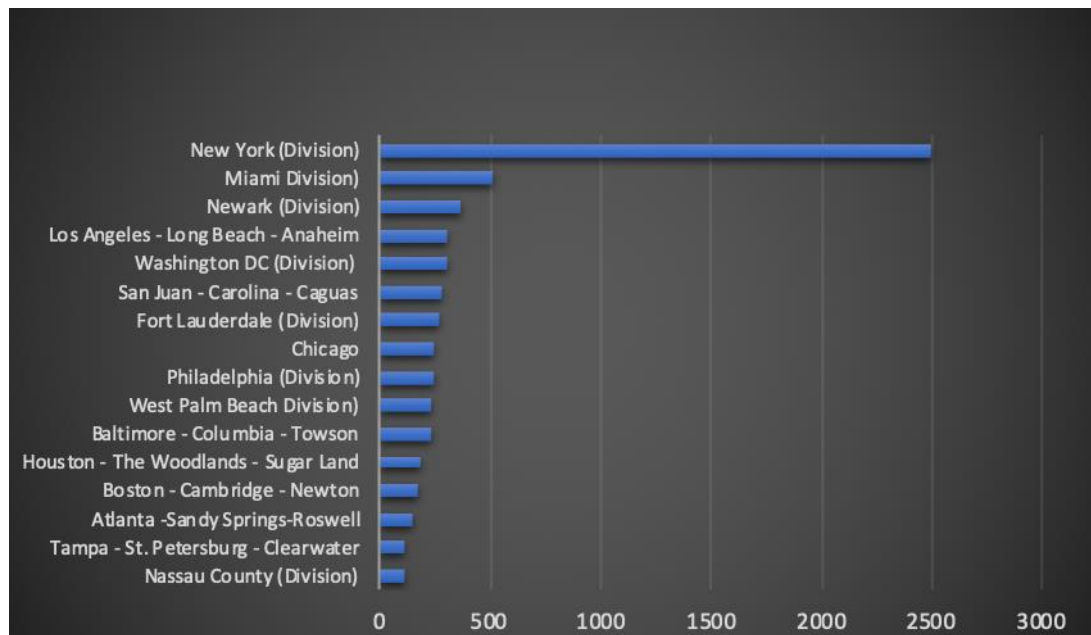


Figure 10: U.S. Cities and Metropolitan Areas with Pediatric AIDS Cases Over 100, 2018
 Source: CDC HIV Surveillance Report, Vol 30, 2018

But when considering the geographic disparities of pediatric AIDS, two regions in the U.S. represented the areas most affected by the disease. Separated by thousands of miles, the Newark-New York City metropolitan region [Figures 2 and 11], and the

southeastern corner of Florida’s Atlantic coast saw the highest rates and cases in the United States. The cities that comprised the highest numbers of children with AIDS in Florida — West Palm Beach, Fort Lauderdale, and Miami — stretched along a roughly seventy-five-mile section of the coast, linked by I-95. Of those places, Miami was the most affected [Figure 12].³⁵

If the spread of the disease in Florida mirrored the sprawling landscape of highways, towns, and populations along the southeastern section of Coastal Florida, the distribution of HIV-AIDS in children in and around New York City likewise mapped onto the unique, densely-packed geography found there. Three of the cities with the highest cases in the northeast — Newark, Jersey City, and New York City — lie along a roughly eight-mile corridor, which is easily traversed by commuter-rail lines. Regardless of the geographic differences between southeastern Florida and the New York metro region, the two areas consistently accounted for a large portion of cases among U.S. cities and metropolitan areas that reported more than twenty cases.³⁶ Those two areas of the country, especially the greater Newark-New York City region, reflected how the rise and concentration of pediatric AIDS was inextricably linked to important changes in post-World War II urban landscapes.

³⁵ CDC “AIDS Report,” 1984 to CDC, *HIV Surveillance Report*, Vol 30, 2018; The map of pediatric AIDS in New Jersey is derived from, Department of Health State of New Jersey, “AIDS Cases, State of New Jersey as of December 31, 1990,” The New Jersey State Library. The Department of Health in New Jersey did not map the geography of pediatric AIDS at the city level. The information for Florida is derived from: Florida Department of Health, HIV/AIDS Section, Division of Disease Control and Health Protection, “Epidemiology of HIV Among Pediatric Cases in Florida, through 2014,” updated May 27, 2016, <http://www.floridahealth.gov/diseases-and-conditions/aids/surveillance/documents/hiv-aids-slide-sets/2014/peds-2014-2.pdf>. In New York, however, the state’s Department of Health mapped pediatric AIDS in New York City since 1988. The pediatric AIDS data are derived from: New York State Department of Health, *AIDS in New York State*, (Albany: New York State Department of Health, 1988) to New York State Department of Health, *AIDS in New York State through 1993* (Albany: New York State Department of Health, 1993).

³⁶ The cumulative cases, here, were drawn from: CDC, *HIV Surveillance Report*, Vol 30, 2018

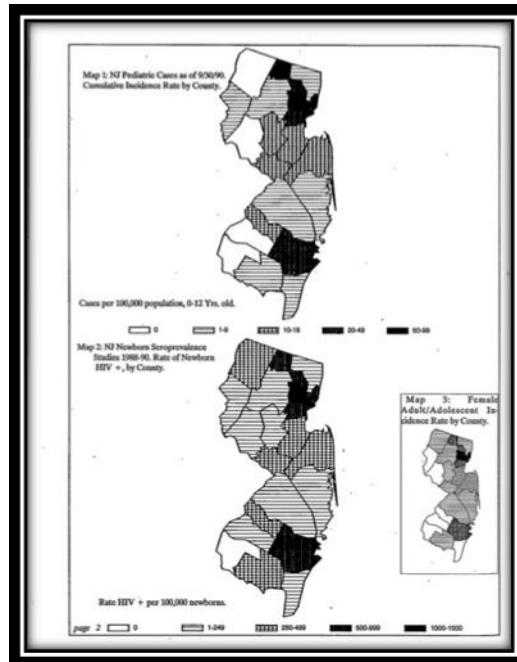


Figure 11: County Map of Pediatric AIDS in New Jersey, 1990
 Note: The counties in northeastern New Jersey are close to New York City. Those Counties include Hudson, Essex, and Passaic
 Source: Department of Health, State of New Jersey, AIDS Cases: State of New Jersey, 1990

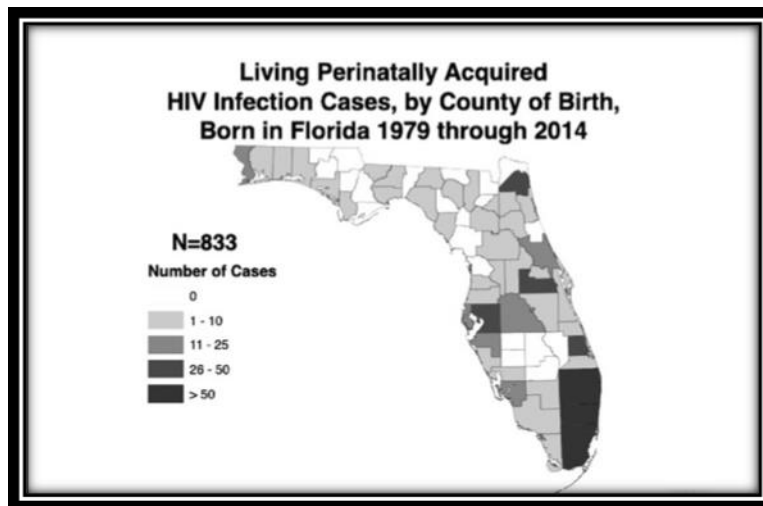


Figure 12: County Map of Pediatric AIDS in Florida, 1979-2014
 Note: Though this map shows “Living perinatally acquired HIV,” the southeastern region of Florida in this map well-illustrates how geographically specific pediatric AIDS was in the state
 Source: Florida Department of Health, HIV/AIDS Section, Division of Disease Control and Health Protection, “Epidemiology of HIV Among Pediatric Cases in Florida, through 2014”

Dislocation, Segregation, Poverty, and the Travels of HIV

In order to understand the geographical distribution of pediatric AIDS, we must also look to some important historical changes that occurred in U.S. cities during the years roughly between 1950 and 1980. During this period, certain urban policies (such as urban renewal initiatives), disinvestment, and changes in employment resulted in the slow upheaval of people, places, and economies that helped create an ecological niche in which HIV thrived. People of color living in, and migrating to, those cities disproportionately bore the brunt of new highway construction, racist zoning policies, racialized segregation, so-called slum clearance, the loss of or exclusion from good paying jobs, and concentrated poverty. This amounted to what the psychiatrist and urban studies scholar Mindy Fullilove calls “root shock” — or the social, emotional, communal, and environmental upheaval brought about by postwar urban policies and other changes — which in turn left many people of color vulnerable to the virus. When considering such changes, we also see how places marked by stark social, cultural, and historical differences — from Central Africa, to Haiti, to Harlem — nevertheless shared a common bond: ecologies of injustice that provided a place where HIV settled and persisted.³⁷

Social upheaval and concentrated poverty helped create the ecological conditions where HIV first found a home among humans. Originating in chimpanzees, the cross-species event that resulted in the emergence of HIV most likely occurred in Central Africa. There, hunters and/or cooks contracted the pathogen after handling chimpanzee

³⁷ My reference to “root shock” and its consequences is derived from: Mindy Thompson Fullilove, *Root Shock: How Tearing up City Neighborhoods Hurts America and What We Can Do about It*, 1st ed. (New York: Ballantine/One World, 2004). Connecting the different regions of the globe in this way is influenced and informed by, Farmer, *Infections and Inequalities*.

carcasses. At some point in the early 1920s, the new HIV virus began to circulate locally in what was the Belgian Congo. European colonization, particularly in Central Africa, disrupted the region's social and physical environments. Colonization transformed the social and economic conditions in the region, which facilitated the migration of central-African populations into cities.³⁸ In cities like Léopoldville (now Kinshasa) and Brazzaville, both of which are now in the Democratic Republic of Congo, poverty pushed women into prostitution. The number of sex partners would increase from the 1920s to the late 1960s, due in large part to economic changes, labor-related migration, and war. In short, the structures of European colonialism helped produce and exacerbate the ecological conditions in which HIV would mutate and spread through sexual intercourse.³⁹

The virus eventually left Léopoldville. Besides circulating through other African countries, HIV eventually traveled outside the continent to places like the Western Hemisphere. Between 1960 and 1966, several thousand teachers from Haiti were sent to the Leopoldville-Congo region. There, one of the dispatched workers contracted the virus and traveled back to Haiti. The scientist Jacque Pepin, who studied and tracked the natural history of HIV, posits that around 1966 that person, "...stayed long enough to

³⁸ The scientist Jacque Pepin argues – based on his research and that of previous scientific investigations – that the virus cross-species event happened in Central Africa. He suggests that the cross-over event happened when chimpanzee hunters and/or cooks, handling chimp carcasses, were exposed to the simian virus that evolved into HIV. He stated that over several decades, "a cross species transmission occurred at least four times for HIV-1, i.e. once for each of groups M, N, O, and P, each of which is thought to reflect distinct cross-species transmission events rather than evolution within humans. It occurred at least for each of the different groups of SIV_{simm} which became HIV-2... Thus, the epidemic of HIV-1 group M was triggered not because a lot of humans were infected directly from chimpanzees but because a rare case of infection managed to spread and multiply, something which all the others that preceded it had not managed to do;" Jacques Pepin, *The Origins of AIDS* (Cambridge: Cambridge University Press, 2011); quote derived from pages 49-50; for his analysis of the "cut-hunter" theory, see 43-58.

³⁹ Pepin *The Origins of AIDS*, 43-58.

start a local chain of sexual transmission.” In sixteen years, eight percent of the women in Port-au-Prince had contracted the virus, reaching a level of infection similar to that seen in the Léopoldville.⁴⁰ A legacy of international ostracism, U.S. imperial interventions, and the inequities of global economic changes helped create the landscape of poverty that pushed, for example, women and other rural residents to Port-au-Prince, a city that saw a large influx of people from the hinterlands. These same factors also helped sustain the conditions that constrained the choices many in the city could make, especially women. Poverty forced them into sex work and “unfavorable unions,” as Paul Farmer has called them, where a woman’s sexual decision-making was perhaps not best described as “consensual.”⁴¹

Meanwhile, as HIV remained off the shores of North America, cities in the United States were undergoing tremendous transformation. One of the largest movements of African Americans in the nation’s history was underway during and after World War II. Escaping rural poverty, violence, and the oppressive social structures of the Jim-Crow South, millions of Black American migrants moved to urban areas in the South, North, and West. Between 1940 and 1980, some five million Black Americans moved out of and through the South. In the 1970s alone, roughly 1.5 million African Americans migrated through the U.S. While many cities saw an increase in Black populations, New York City and northeastern New Jersey saw some of the highest numbers, with just over 750

⁴⁰ Pepin, 230–31; quote derived from 230.

⁴¹ For the historical and structural forces that led to poverty in Haiti, see Paul Farmer, *AIDS and Accusations Haiti and the Geography of Blame* (Berkeley: University of California Press, 1992), 164-190; My reference to sex work comes from Farmer’s *AIDS and Accusations*, 130-132. For how rural poverty pushed women into urban poverty, see, Paul Farmer, “Women, Poverty, and AIDS,” in Paul Farmer, Margaret Connors, and Janie Simmons, eds., *Women, Poverty, and AIDS: Sex, Drugs, and Structural Violence*, 2nd edition (Monroe, Me: Common Courage, 2011).

thousand people settling in the region by 1980. Southern cities saw demographic shifts as well: in Miami, the Black population more than doubled between 1940 and 1960, growing from just under fifty thousand to just over one hundred thirty-seven thousand.⁴²

That postwar demographic shift helped facilitate important changes in the United States. The Second Great Migration of African Americans was one the more important engines of political and cultural change in the United States.⁴³ The urbanization of black Americans during this era fueled the Civil Rights Movement in the North and South, and the cultural energy they supplied cities turned many urban centers into places that helped change journalism, music, literature, and sports. Employment in cities, especially in manufacturing, also helped provide economic mobility and security for Black Americans. In some cases, southern-born Black men gained greater employment than those born in norther states and cities; women, however, earned close to half of what men did.⁴⁴

Besides African-American migration, Puerto Ricans and Haitians were also moving into Newark, New York, and Miami. Similar to African Americans, Puerto Ricans, for example, migrated to the mainland in larger numbers. Just between 1945 and 1959, the number of Puerto Ricans settling in East Harlem grew from twenty thousand to sixty-three thousand. By 1990, they comprised 52 percent of those living in the area of Manhattan.⁴⁵ In Miami, though much later, Haitians began to migrate to the city. Between 1977 and 1981, roughly sixty thousand Haitian refugees settled in the city. For

⁴² James N. Gregory, "The Second Great Migration" in Kenneth L. Kusmer and Joe W. Trotter eds., *African American Urban History since World War II* (Chicago: University of Chicago Press, 2009).

⁴³ Gregory, "The Second Great Migration," 37.

⁴⁴ Gregory, "Second Great Migration; quote derived from 37

⁴⁵ Bourgois, *In Search of Respect*, 7; Zipp, *Manhattan Projects*, 262.

perspective, that represented one-fifth of Haitian refugees that settled in New York City.⁴⁶

Though some racial and ethnic minorities benefited from the migration to cities, many faced economic hardships. In the cities that became the epicenters for pediatric AIDS — as was the case in other U.S. cities — Black and Latinx populations experienced declining employment opportunities and increasing rates of poverty. Just as those newcomers began arriving in cities, low-skilled jobs had already begun to decline. For example, the process of deindustrialization in Newark began around 1930, and while the city retained a number of white-collar jobs by the 1960s, only about one-third of those jobs were occupied by Newark residents.⁴⁷ New York City lost some five hundred thousand manufacturing jobs between 1947 and 1976, which had profound effects on Black and Latinx residents in places like the South Bronx. For immigrant groups that came to the U.S. during the early twentieth century, New York City particularly emerged as the “Golden Door” for social and economic upward mobility. But similar routes for upward mobility, and the escape from poverty, eluded Black and Latinx groups as they began settling in New York City, Newark, and Miami after World War II.⁴⁸

In addition to the economic and social impacts brought by deindustrialization, many Black and Latinx groups experienced racist housing policies and employment discrimination, which resulted in a geography of racialized segregation and concentrated

⁴⁶ Portes, *City on the Edge*, 51–58.

⁴⁷ Rabig, *The Fixers*, 1–19.

⁴⁸ For reference to the “Golden Door” and the loss of employment, see: Evelyn Gonzalez, *The Bronx* (New York: Columbia University Press, 2004), 118. Information about the history of the South Bronx is also informed by, Jill Jonnes, *We’re Still Here: The Rise, Fall, and Resurrection of the South Bronx*, 1st ed. (Boston: Atlantic Monthly Press, 1986.); For a brief description of the socioeconomic conditions of Puerto Ricans in Newark, see: Sabrina Chase, *Surviving HIV/AIDS in the Inner City: How Resourceful Latinas Beat the Odds* (Piscataway: Rutgers University Press, 2011).

poverty. In their effort to retain white residents in Miami, the city's postwar redevelopment initiatives pushed many of its Black residents out of the downtown area during the mid-to-late 1960s. City officials zoned areas of northwest Miami for the construction and concentration of low-income housing. Many of the city's African American and Haitian residents were either relocated or settled in the adjoining suburb of Brownsville, as well as neighborhoods within Miami's official boundaries. Those included Liberty City, Allapattah, Opa-locka, Overtown, and Little Haiti [Figures 13 and 14].⁴⁹

⁴⁹ Information is derived from and informed by the following: Hirsch, *Making the Second Ghetto*; Sugrue, *The Origins of the Urban Crisis*; Connolly, *A World More Concrete*; Douglas S. Massey, *American Apartheid: Segregation and the Making of the Underclass* (Cambridge, Mass.: Harvard University Press, 1993); Douglas S. Massey and Nancy A. Denton, "Suburbanization and Segregation in U.S. Metropolitan Areas," *American Journal of Sociology* 94, no. 3 (1988): 592–626.



Figure 13: Map of Black Population in Miami, Florida, 1980

Note: the area of Little Haiti is roughly between Brownsville and the west coast of the bay separating Miami from Miami Beach. Note the high levels of racial segregation in and around Brownsville

Source: Total Population: Black, 1980. Social Explorer, (based on data from U.S. Census Bureau; accessed December 1, 2019)

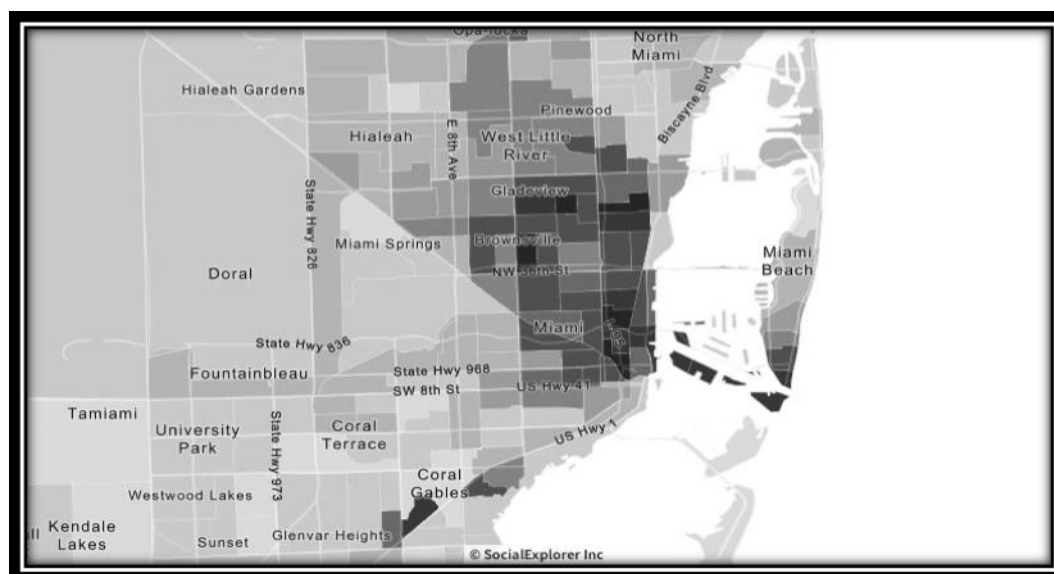


Figure 14: Map of Poverty in Miami, Florida, 1979

Note: This map shows how the concentration of poverty closely maps with the racial segregation in Miami

Source: Total Population, Poverty Status in 1979 (short version), Below Poverty Level. Social Explorer, (based on data from U.S. Census Bureau; accessed December 1, 2019)

As in Miami and other cities, the overlapping geographies of racial-ethnic segregation and poverty were present in Newark and New York City as well. The latter included areas of the city like Harlem, East Harlem, the South Bronx, and Brownsville in Brooklyn. In Newark, the distribution of people of color was largely isolated in the Central, North, and West Wards of the city. The racial segregation and concentration of poverty in Newark was also representative of the racialized development of the nation's suburbs, which favored white residents. This resulted in what historian Liz Cohen called a "complicated mosaic" of racialized, residential patterns in and around the Newark-New York City region, a pattern that was present in other parts of the country. [Figures 15 and 16]⁵⁰

⁵⁰ Gonzalez, *The Bronx.*; Rabig, *The Fixers*; Krasovic, *The Newark Frontier*; quote is derived from, Cohen, *A Consumers' Republic*, 213.

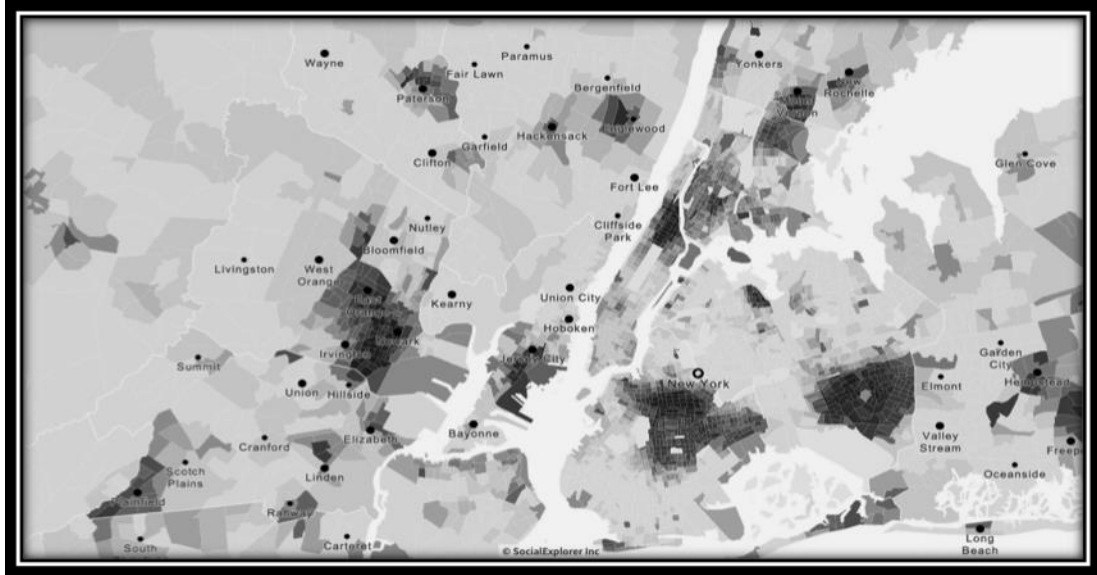


Figure 15: Map of Black Population in the Newark-New York City Metropolitan Area, 1980

Note: This map not only illustrates Cohen’s depiction of the region. Note the similar “mosaic” within New York City’s five boroughs and nearby suburbs

Source: Total Population: Black, 1980 Social Explorer, (based on data from U.S. Census Bureau; accessed December 1, 2019)



Figure 16: Map of Poverty in the Newark-New York City Metropolitan Area, 1979

Note: like Miami, the geography of concentrated poverty was mapped onto the geography of racial segregation

Source: Total Population, Poverty Status in 1979 (short version), Below Poverty Level, Social Explorer, (based on data from U.S. Census Bureau; accessed December 1, 2019)

Contributing to the racial segregation and concentration of poverty were the federal and local urban renewal policies that profoundly reshaped many urban environments after the Second World War. In the roughly three decades after the war, the nation experienced what historian Francesca R. Ammon called a “culture of clearance.” From 1950 to 1980, 7.5 million residential dwellings were demolished as part of urban renewal initiatives. The reshaping of many cities included new highway construction and slum clearance, as well as the building of massive public housing blocks, cultural institutions, and academic medical centers.⁵¹ Thousands of families in Newark, New York, and Miami were displaced during this era, with families of color being disproportionately affected by those processes. From 1950 to the late 1960s alone, 1,386 families were moved from Central Miami, 100 percent of them were families of color. In Newark, 5,572 were displaced, 65 percent of whom were families of color. And in New York City, 29,464 families were displaced, 41 percent of those were families of color; in Harlem, some 3,000 families of color were displaced.⁵²

The physical transformation of American cities benefitted some neighborhoods, but it also hurt others. Urban renewal helped exacerbate the processes of deindustrialization; it also made worse, and even perpetuated, social and class divisions emerging during the post-World War II years. Besides “upscaling” some dilapidated

⁵¹ Francesca Russello Ammon, *Bulldozer : Demolition and Clearance of the Postwar Landscape* (New Haven: Yale University Press), 7.

⁵² Digital Scholarship Lab, “Renewing Inequality,” *American Panorama*, ed Robert K. Nelson and Edward L. Ayers, accessed December 1, 2019, <https://dsl.richmond.edu/panorama/renewal/#view=0/0/1&viz=cartogram&text=citing> This projected used data for families that were displaced, so they did not account for individuals who were also displaced by urban renewal initiatives in the U.S. between 1950 – 1960. Also, there is a large scholarship about urban renewal in the United States. The works cited below reflect a sample of that literature as it relates to the cities that are the focus of this chapter.

neighborhoods, the process of urban renewal displaced poor communities of color, pushing them to large public housing blocks, a process which ultimately reinforced racial segregation and concentrated the poor into particular areas of the city.⁵³ White flight added to the problem, resulting in declining tax revenue for cities and increasing the amount of abandoned properties. That was certainly the case in New York City. Locally, as was the case in the South Bronx, the physical reordering of such areas also resulted in the deterioration of the social environment. As blocks were razed, rebuilt, and disrupted by highway construction, for example, the social fabric of the neighborhoods dissolved. Some left before their neighborhood was affected, others could not. For those remaining in places like the South Bronx, the fractured socio-physical landscape contributed to further blight.⁵⁴

By the mid-1970s, northeastern cities were particularly affected by declining populations, economic recession, the loss of employment, and urban renewal policies. While residents in Newark and New York City took back some control of their urban environments, city officials implemented disinvestment plans that further disrupted an already fragile ecosystem.⁵⁵ In response to declining populations in parts of New York City — areas such as the South Bronx and Brownsville Brooklyn — as well as the reduction in housing stock, declining tax revenues, and the fiscal crisis of the mid-1970s,

⁵³ Zipp, *Manhattan Projects*, 21.

⁵⁴ Gonzalez, *The Bronx*, 122–24; Information about White Flight is derived from: Sugrue, *The Origins of the Urban Crisis* and Cohen, *A Consumers' Republic* For the historical rethinking of White Flight, see: Heather Ann Thompson, “Rethinking the Politics of White Flight in the Postwar City: Detroit, 1945-1980.” *Journal of Urban History* 25, no. 2 (1999): 163-198.

⁵⁵ See, for example: Komozi Woodard, *A Nation within a Nation : Amiri Baraka (LeRoi Jones) and Black Power Politics* (Chapel Hill, N.C.: University of North Carolina Press, 1999); Rabig, *The Fixers*; Nick Juravich, “‘We the Tenants’: Resident Organizing in New York City’s Public Housing, 1964-1978,” *Journal of Urban History* 43, no. 3 (May 1, 2017): 400–420. Themis Chronopoulos, “The rebuilding of the South Bronx after the fiscal crisis.” *Journal of Urban History* 43, no. 6 (2017): 932-959.

the city government withdrew municipal services from those regions of the city. One of those services was firefighting companies. In 1976, Roger Starr, the administrator of Housing and Development, called such policies of withdrawal “planned shrinkage.” Though Mayor Beame of New York City thought the policies were inhumane, the strategic abandonment of specific areas the city deemed beyond rehabilitation were nevertheless adopted. The adoption of such policies thus reflected how some of the city’s elites ultimately determined which parts of New York were worth saving and which ones were not. In 1977, fires further destroyed parts of the South Bronx, pushing its residents elsewhere, and leaving that part of the borough with more abandoned buildings and land.⁵⁶

Though planned shrinkage was specific to New York, it was representative of the drastic changes that occurred in American cities leading up to HIV’s arrival in North America. In fact, the first documented case of pediatric AIDS occurred the same year that some of the most devastating fires occurred in parts of the Bronx: 1977. Furthermore, the drastic changes to the urban landscapes in Newark, New York City, Miami, and a host of other cities across the U.S., coexisted with the prevalence of heroin.⁵⁷

This upheaval, and the presence of a powerful (and addictive) coping mechanism, was tersely captured by one man’s return to his mother’s home in Harlem. In 1965, Teddy was arrested and sentenced to prison for an alleged armed robbery and attempted

⁵⁶ Rodrick Wallace, “A Synergism of Plagues: ‘Planned Shrinkage,’ Contagious Housing Destruction, and AIDS in the Bronx,” *Environmental Research* 47, no. 1 (October 1, 1988): 1–33; Deborah Wallace, *A Plague on Your Houses : How New York Was Burned down and National Public Health Crumbled* (New York: Verso, 1998), 21–39 On Mayor Beame and “planned shrinkage,” see Chronopoulos, “The rebuilding of the South Bronx.”

⁵⁷ Eric C. Schneider, *Smack : Heroin and the American City* (Philadelphia: University of Pennsylvania Press, 2008).

murder. In 1977 he returned to a drastically changed urban landscape. As he traveled uptown, he was shocked to see the subway trains covered in graffiti and the platforms strewn with trash. As he told a group of oral historians, Teddy remembered saying to himself, “What the fuck happened?” He left the subway at 135th street: “I looked at the neighborhood and there weren’t any more houses, just bricks and garbage and shit piled up. I said ‘Goddamn!’” It was summer, and he remembered how the streets were often filled with people that time of year, with kids playing on the block. In 1977, “it was almost like a ghost town.”⁵⁸

Teddy finally reached his mother’s home, which was also in poor shape. “Wow!” he thought after seeing the once well-maintained building turned into a place with falling lights, crumbling plaster, marked-up walls, and garbage behind the stairs. He asked his mother “what happened” to the “decent” house they lived in on Seventh Avenue. Arriving at home at night, he caught only a glimpse of some of the changes. In the morning, however, he said: “I...looked out the window...it was just completely turned around. Across the street the houses were boarded up, nailed up. And the first thing I see is a guy out there selling dope.”⁵⁹

⁵⁸ David T. Courtwright, Herman Joseph, and Don Des Jarlais, *Addicts Who Survived an Oral History of Narcotic Use in America before 1965*, 1st ed. (Knoxville : University of Tennessee Press, 1989), 254.

⁵⁹ Ibid Courtwright, *Addicts Who Survive*, 254.

Drugs, Shooting Galleries, and HIV in the United States

By the time Teddy returned home in 1977 the virus had already made its way to North America through blood and bodies.⁶⁰ Teddy's shock at seeing his neighborhood so drastically changed, which included someone selling drugs on his street — even though Teddy was a heroin user himself — also well-illustrated the environmental conditions that helped facilitated the spread of HIV in during the late 1970s and early 1980s. The destructive transformation of the physical, social, and psychological landscapes in parts of New York City forced some residents to seek out coping strategies that would help them survive in such places. In fact, in parts of New York City and Newark, the landscape of abandoned buildings made ideal places to use and sell drugs like heroin (and later, cocaine).⁶¹ But such conditions were found in other cities as well; places that did not become hotbeds of pediatric AIDS. Understanding this phenomenon thus requires an exploration into how the economy and geography of IV drug use, coupled with racialized segregation, resulted in pediatric AIDS becoming a problem for some U.S. cities — and some American families — but not others.

⁶⁰ Pepin suggests, that the virus entered the blood supply through blood-plasma sellers overseas. At this point, along with evidence from other countries, the virus had made its way into the international trade of blood plasma. With blood-plasma making its way to the U.S., coupled with gay sexual encounters among men traveling to Haiti from the U.S., the virus — unknown to everyone at the time — eventually entered North America at some point in the early 1970s. Besides circulating among gay men, the virus was also circulating among IV drug users. Pepin also acknowledges that the evidence is less conclusive for the spread of HIV in the blood plasma in Haiti, but he shows how the selling/collection of plasma in other countries — China, India, and Mexico — revealed HIV there. See: Pepin, *The Origins of AIDS*, 231–34; Richard McKay provides a good summary of Pepin's research as it relates to our understanding of how HIV travel from the African continent to North America; see, Richard Andrew McKay, *Patient Zero and the Making of the AIDS Epidemic* (Chicago: The University of Chicago Press, 2017).

⁶¹ This is informed by the following: Caroline Jean Acker, *Creating the American Junkie : Addiction Research in the Classic Era of Narcotic Control* (Baltimore: Johns Hopkins University Press, 2002), 225; Acker, “How Crack Found a Niche in the American Ghetto.”

From the late 1970s through the early 1980s, the U.S. saw a spike in heroin supply. Since before the Second World War, the U.S. experienced waves of international heroin entering the country, which often correlated with levels of use. After a lull in the supply during the early 1970s, more heroin entered the country at the end of the decade. A number of American cities were important marketplaces for the international heroin trade. They included Chicago, Detroit, Washington D.C., Philadelphia, and New York; but the latter was the most important port for heroin entering the U.S. In fact, according to historian Eric C. Schneider, New York City was the most important marketplace for the selling and distribution of heroin in the United States at the time. While New York's status as an important node in the international trade of heroin dated back to before the Second World War, conditions in many American cities by the 1970s also helped increase the demand for the drug.⁶² Moreover, in poor urban areas with little access to employment, heroin became endemic.⁶³

Whether it was the “root shock” of urban-renewal policies, exclusion from employment, systemic racism, or the general hopelessness associated with all of those phenomena, some turned to heroin to cope. In 1985, a group of social scientists published *Life with Heroin: Voices from the Inner City*, in which they succinctly summarized why

⁶² Schneider, *Smack*, 1–16; 35; 98-115; 100; 115-141;160-195; *Investigation of Narcotics Trafficking and Money Laundering in Chicago a Report of the Select Committee on Narcotics Abuse and Control, Ninety-Fifth Congress, First Session* (Washington, D.C.: U.S. G.P.O. 1978), United States., *Increased Heroin Supply and Decreased Federal Funds: Impact on Enforcement, Prevention, and Treatment: A Report of the Select Committee on Narcotics Abuse and Control, Ninety-Sixth Congress, Second Session* (Washington, D.C.: G.P.O., 1980).

On the lull in heroin supply to New York City, see also: Donald Des Jarlais, “Heroin Activity in New York City, 1970 – 1978, *The American Journal of Drug and Alcohol Abuse*, 7, Iss 3 and 4, (1980): 335-346. For trends in heroin use in Newark/Essex County, New Jersey, see: John F. French, Chief, Office of Data Analysis and Epidemiology, Alcohol, Narcotic and Drug Abuse Unit, New Jersey Department of Health, “Drug Trends in Newark, New Jersey, June, 1986, Box 1, Folder 22, Department of Health, Commissioner’s Subject Files, New Jersey State Archive, Trenton, NJ.

⁶³ Courtwright, et al, *Addicts Who Survived*, 18.

some people used the drug. Speaking specifically about poor, African Americans seeking work in northern urban areas, the authors noted how those cities proved to be “inhospitable” to many of the newcomers. They argued that: “[m]any of the minority newcomers became victims of unemployment, poverty, and racial discrimination, and developed a sense of futility. Is it surprising that they sometimes coped with this situation by turning to drugs?”⁶⁴ Children were also socialized in an environment where, at least in some areas of cities, the use of heroin was omnipresent and normalized.⁶⁵

Some users vividly and poignantly described their use of heroin as a way to cope with their social and environmental circumstances. At some point in the early 1980s, Nathan, who lived in Washington D.C., told researchers that “[a] black man has no control over what goes down in this world... You get better education where the money is, where the white is you get better education. There's better jobs; there's better houses; better places to buy your groceries; you get more for your money.” He explained how he too sought the “All-American Dream,” but he asked: “[w]hat kind of dreams can a Black man have in this country? They control those things. Some of us are able to deal and accept that and those are the ones that don't have to use drugs.”⁶⁶

When it came to using drugs like heroin or cocaine, an important feature of the built environment, and the economy of drug use, might help explain the proliferation of HIV-AIDS in some areas: the “shooting gallery.” A secluded space in a house or apartment to inject drugs, shooting galleries were found in New York, Washington D.C.,

⁶⁴ Bill Hanson, George Beschner, James M. Walters, and Elliott Bouvelle eds, *Life With Heroin: Voices from the Inner City* (New York, NY: Lexington Books, 1985), 3.

⁶⁵ Courtwright et al, *Addicts Who Survived*, 18.

⁶⁶ Bill Hanson ed, *Life with Heroin*, 20–29; quotes derived from 19 and 20. For an earlier ethnography of urban heroin use, see: Michael Agar, *Ripping and Running: A formal Ethnography of Urban Heroin Addicts* (New York: Seminar Press, 1973).

and Baltimore; in Miami, they were referred to as “get-off” houses. Most often, though not exclusively, shooting galleries were located in abandoned buildings, which was certainly the case in New York City and other places in the northeast and mid-Atlantic states. Given the stock of abandoned properties in the South Bronx, parts of Manhattan, Brooklyn, and Newark, there was undoubtedly ample space for setting up a shooting gallery, especially if those buildings still had running water and stoves so that users could cook their heroin⁶⁷

Not all users frequented shooting galleries, but for those who did, the space offered a few important amenities. Ben, in Philadelphia, avoided those spaces. He did not want to spend money on renting a “dirty” syringe, and he told researchers, “[g]alleries ain’t where it’s at...[t]hey be definitely [for] hard core junkies...an’ people be shootin’ blood all over you.” Others used the galleries to quickly consume the drugs as to avoid

⁶⁷ Don C. Des Jarlais, Samuel R. Friedman, and David Strug, “AIDS and Needle Sharing Within the IV-Drug Use Subculture,” in Douglas A. Feldman and Thomas M. Johnson, eds., *The Social Dimensions of AIDS: Method and Theory* (New York: Praeger, 1986). Information about shooting galleries in other cities is derived from: “9 Are held in Dope Case,” *The Baltimore Sun*, June 8, 1967; Gerald H. Friedland et al., “Intravenous Drug Abusers and the Acquired Immunodeficiency Syndrome (AIDS): Demographic, Drug Use, and Needle-Sharing Patterns,” *Archives of Internal Medicine* 145, no. 8 (August 1, 1985): 1413–“Shooting Gallery’ Raid Nets Five,” *The Baltimore Sun*, March 19, 1969; “Six Seized in City on Heroin Counts,” *The Baltimore Sun*, May 23, 1970; “Raid on ‘Shooting Gallery’ Brings Arrest of 4 Men,” *The Baltimore Sun*, June 29, 1970; Keller McCartney, “8 Arrested in Raid of Drug-Shooting Gallery,” *Atlanta Constitution*, April 22, 1970; “Iowa’s Hughes Threatened in Harlem ‘Shooting Gallery,’” *The Baltimore Sun*, June 26, 1971; Sandy Smith, “Busted in a Shooting Gallery,” *The New York Times*, March 25, 1972; “Miami Police Raid Dope-Shooting Gallery,” *The Baltimore Sun*, December 24, 1972; Loretta Tofani, “City Owns a Heroin ‘Shooting Gallery,’” *The Washington Post*, June 24, 1979; J Bryan Page et al, “Intravenous Drug Use and HIV Infection in Miami,” *Medical Anthropology Quarterly*, 4, no. 1 (March, 1990): 56-71. For a more contemporary ethnography of the shooting gallery, see: Philippe Bourgois, “Just Another Night in a Shooting Gallery,” *Theory, Culture & Society* 15, no. 2 (1998): 37-66. The extent of abandoned properties in Newark is difficult to assess. However, the city of Newark sought to institute a comprehensive health plan for the city, in which they mapped significantly deteriorated properties: James A Buford, *Newark Comprehensive Health Plan, 1976-1977*, Newark Health Planning Agency (Newark, NJ: Department of Health and Welfare, 1977), Rutgers University Special Collections, Medical Library, Newark NJ; Camilo Vergara, who photographed Newark and other postindustrial cities provides some evidence for deteriorated and abandoned properties in Newark, see: Camilo J. Vergara, *The New American Ghetto* (New Brunswick: Rutgers University Press, 1995.)

arrest for possession of illegal narcotics. They were also a place to socialize and get information from other users. Since it was also illegal in many places to carry drug-using equipment, such as syringes, this made so-called “cash” galleries attractive to some users because they could rent a syringe without the threat of arrest for possession of drug paraphernalia.⁶⁸

Such spaces were also part of the larger economy of illicit narcotics. It provided some poor people a way to earn money. Don C. Des Jarlais and Samuel R. Friedman, who studied IV drug users before and during the AIDS epidemic, showed how shooting galleries were part of that economy in New York City. In an “eyesore” of a building in New York, there were two cash galleries that offered services to users. On different floors, users could rent syringes from the proprietors of the shooting gallery. The price for renting a syringe in that particular building ranged from one to two dollars. One of the proprietors also charged one dollar for assisting users in injecting their drugs. These types of galleries were found in other cities, such as Washington, D.C., Chicago, and Miami.⁶⁹ The number of shooting galleries in any given area is difficult to assess. But in 1979, a *Washington Post* article interviewed a man who ran a cash gallery who told the reporter that there were 100 galleries in Northwest Washington D.C. alone. Though difficult to verify such a claim, the location of his shooting gallery nonetheless helps illustrate the geography of such spaces in relation to a city’s illicit drug marketplaces.⁷⁰ Of course, the use of illicit narcotics was *not* relegated to poor urban communities of color.

⁶⁸ Hanson, *Life of Heroin*, 42-43; quote derived from 43. See also, Des Jarlais and Friedman, “AIDS and Needle Sharing.”

⁶⁹ Des Jarlais and Friedman, “AIDS and Needle Sharing,” 116-120.

⁷⁰ Tofani, “City Owns a Heroin ‘Shooting Gallery,’”; J Bryan Page et al, “Intravenous Drug Use and HIV Infection in Miami,”; Lawrence J. Ouellet, et al., “Shooting Galleries and HIV Disease: Variation in Places for Injecting Illicit Drugs,” *Crime and Delinquency*, Vol 37, No 1, (January 1991): 64-85.

Suburbanites used heroin in the 1970s, and it is safe to assume that continued through the early 1980s. Though unclear how they consumed heroin, it is equally safe to assume that they did not frequently cash galleries to rent syringes; some accounts suggest that the drugs were purchased in places like New York City or Detroit, and resold or used in nearby suburbs.⁷¹

If users frequented galleries as to avoid carrying illegal drug-using technologies, or because it was perhaps less expensive to rent syringes, such practices made the once common use of galleries more dangerous once HIV arrived in the mid-to-late 1970s. In addition, sharing needles, especially among friend groups, was common before HIV-AIDS, and understood by some users to be a safer way to consume their narcotics (e.g. avoiding arrest for possession of a syringe, and they presumed that sharing syringes among friends reduced the chance of contracting diseases). But once HIV arrived, the shooting gallery became the most important technological system that helped rapidly spread the blood-borne disease in certain areas of the country, even across friend groups that did not frequent such places.⁷²

The location and use of shooting galleries are undoubtedly important in understanding the geography of pediatric AIDS in some cities. Consider the disparity in HIV-AIDS among heterosexual IV drug users in different regions of the U.S. In one study, conducted by the National Institutes of Drug Abuse, New York and New Jersey “accounted for 74 percent of all heterosexual cases [of AIDS] among...” IV drug users

⁷¹ Schneider, *Smack*, 142–58.

⁷² Don Des Jarlais et al, “The Sharing of Drug Injection Equipment and the AIDS Epidemic in New York City: The First Decade,” in Robert J. Battjes and Roy W. Pickens eds., *Needle Sharing among Intravenous Drug Abusers : National and International Perspectives, NIDA Research Monograph, 80* (Rockville, MD: National Institute on Drug Abuse, 1988), 167.

by 1987. California, on the other hand — which reported the second highest number of cumulative AIDS cases in the country after New York — “accounted for 2 percent of all [AIDS] cases...” among heterosexual IV drug users.⁷³ In San Francisco and New York City, those disparities were also present. A 1987 study, which focused on heterosexual IV drug users in San Francisco, found that 10 percent of those studied tested positive for HIV-AIDS. They compared that to a study that showed how in New York (specifically in Harlem and Brooklyn) 61 percent of those studied tested positive for the disease. The public health researchers concluded that "the use of 'shooting galleries'...is common in New York City but less so in San Francisco. The social isolation of addicts and lack of 'shooting galleries' in San Francisco may have provided a protective barrier to early introduction of HIV to drug users here [San Francisco]"⁷⁴

The markets for drugs like heroin, along with shooting galleries, were also found in the poorest areas of some American cities. In New York, by the 1970s, two of the city’s largest heroin markets were in and around 116th Street and Eight Avenue (Harlem), close to Teddy’s mother’s home [Figure 17]. The other was in the Lower East Side of Manhattan, which provided easy access for those in New Jersey, Brooklyn, and nearby suburbs, because of the nexus of roads and commuter rail lines that intersected there. In

⁷³ Harry W. Haverkos, “Overview: HIV Infection Among Intravenous Drug Abusers in the United States and Europe,” in *Needle Sharing Among Intravenous Drug Abusers*, 9; CDC “AIDS Weekly Surveillance Report,” December 28, 1987.

⁷⁴ Richard E. Chaisson, et al. "Human immunodeficiency virus infection in heterosexual intravenous drug users in San Francisco." *American Journal of Public Health* 77, no. 2 (1987): 169-172, quote derived from 171.

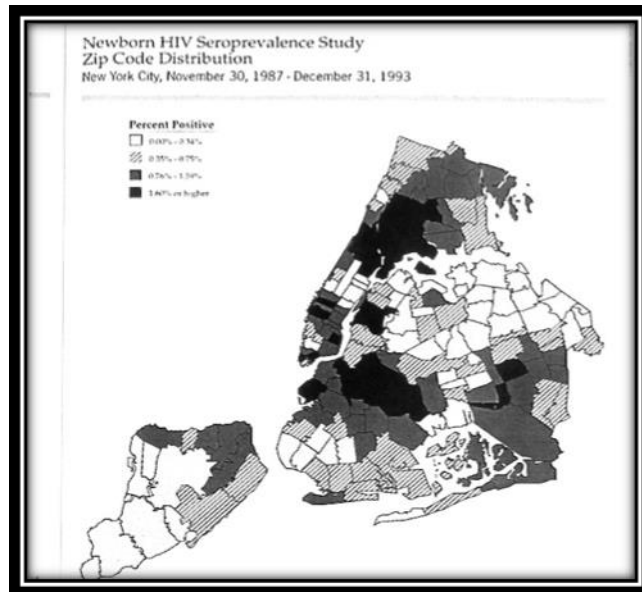
turn, shooting galleries emerged near such “coping” areas to allow for safe and quick use of the drugs for users that sought out such places as to avoid arrest or to use a syringe.⁷⁵



Figure 17: Map of Poverty and Heroin Marketplaces in New York City, 1979

Note: Red markers roughly indicate major drug marketplaces in New York City (Information derived from Schneider, Smack). Also, note the close proximity of heroin marketplaces to the geography of pediatric AIDS (see map below)
Source: Total Population, Poverty Status in 1979 (short version), Below Poverty Level, Social Explorer, (based on data from U.S. Census Bureau; accessed December 1, 2019)

⁷⁵ Schneider, *Smack*, 140; 187-188; In a number of accounts, the “coping” areas and shooting galleries were found near drug marketplaces: see, for example, George M. Beschner and William Brower, “The scene,” and James M. Walters, “Taking Care of Business” Updated: A Fresh Look at the Daily Routine of the Heroin User,” in *Life with Heroin*. When considering the transportation connection between Newark, Jersey City, and Lower Manhattan, the areas is conveniently linked through the PATH Train, which is run by New Jersey/New York Port Authority. This information is derived from: Michael N. Danielson and Jameson W. Doig, *New York: The Politics of Urban Regional Development*, chapter, “Mass Transportation and the Limited Capabilities of Government,” (Berkeley: University of California Press: 1982); Richard M. Carpino et al, “Community and Drug Use among Gay Men: The Role of Neighborhoods and Networks” *Journal of Health and Social Behavior*, 52, no. 1 (March 2011): 74-90; David Goodwin, *Left Bank of the Hudson: Jersey City and the Artists of 111 and 1st* (New York: Fordham University Press, 2018); see chapter “Crossing the Hudson.”



We can see, therefore, how patterns of poverty, IV drug use, and the increase in pediatric AIDS during the late 1980s possess similar geographic features. A retrospective study of HIV-AIDS in women partially explains the particular concentration of pediatric AIDS. In 1991, scientists published an article in the *Journal of the American Medical Association* that showed how, from 1981 to 1990, the vast majority of women with the disease were on the east coast and in Puerto Rico. Of the 15,493 cases of the disease in women, 51 percent were reported to have contracted the disease through IV drug use, 21 percent through sexual contact with a partner that was an IV drug user, and 9 percent through sexual contact with a non-IV drug using partner. By 1989, they estimated that “6000 infants were born to HIV-infected women in the United States, and probably about 1500 to 2000 of these infants were infected perinatally.” The states with more than 20 cases of HIV-AIDS per 100,000 women included New York, Florida, New Jersey,

Connecticut, Maryland, Washington D.C., and Puerto Rico.⁷⁶ Shooting galleries were common in cities found in some of those states. They included the Newark-New York City area, Baltimore, Washington D.C., and the “get-off” houses in Miami.⁷⁷

But if the shooting gallery was one of the primary sites responsible for the rapid spread of HIV-AIDS, we must consider how it was one node in a system of HIV-AIDS transmission. After all, the shooting gallery was merely a technological system for consuming illicit drugs. It emerged within a larger economy of narcotics that was in large part a response to changes in urban environments and the concentrated and inescapable poverty embedded in some communities of color from the 1960s to the early 1980s and beyond. Yet not everyone in those communities used narcotics, and for those who did, they may not have frequented shooting galleries. The phenomenon of race-based sexual

⁷⁶ Tedd V. Ellerbrock, et al, “Epidemiology of Women with AIDS in the United States, 1981 Through 1990: a comparison with heterosexual men with AIDS” *Journal of the American Medical Association (JAMA)* 265, no 22 (1991): 2971-2975.

⁷⁷ Des Jarlais, Friedman, Strug, “AIDS and Needle Sharing Within the IV-Drug Use Subculture”; “9 Are held in Dope Case,” “Shooting Gallery’ Raid Nets Five,” “Six Seized in City on Heroin Count,” “Raid on ‘Shooting Gallery’ Brings Arrest of 4 Men,”; Keller McCartney, “8 Arrested in Raid of Drug-Shooting Gallery”; “Iowa’s Hughes Threatened in Harlem ‘Shooting Gallery’”; Sandy Smith, “Busted in a Shooting Gallery”; “Miami Police Raid Dope-Shooting Gallery,”; Loretta Tofani, “City Owns a Heroin ‘Shooting Gallery,’” J Bryan Page et al, “Intravenous Drug Use and HIV Infection in Miami.” In 1989, researchers published a study in *The New England Journal of Medicine* showing how social setting and drug use patterns were strong predictors of high rates of HIV-AIDS in some populations IV drug users. Of note was the prevalence of shooting galleries in a particular area of the city. The location of this study is important as well. The researchers relied on data from drug users that were treated at a methadone center in the Bronx. It should also be noted that the researchers were interested in why Black and Hispanic IV drug users were more likely to test positive with HIV. They attempted to understand if race may have been one of the determining factors in the distribution of HIV-AIDS among drug users, suggesting that injecting “drugs in shooting galleries and sharing needles with strangers and acquaintances [was] more frequent among blacks and Hispanics.” Whereas, the researchers also suggested, sharing needles among “close friends and relatives” was more frequent among whites. This is not to suggest that focus on race, as a determining factor, compromises the observations about the high rates of HIV-AIDS in the Bronx, which was tied to the geography and use of shooting galleries in the that part of New York City. However, the use of race as a research variable was nonetheless problematic. For the study, see: Ellie E Schoenbaum et al “Risk Factors for Human Immunodeficiency Virus Infection in Intravenous Drug Users,” *The New England Journal of Medicine*, 321, no. 13 (1989): 874-879

patterns and racialized segregation also helps us understand the unique distribution of pediatric AIDS in the United States.

Public health scientists who studied the racial disparities of HIV-AIDS have shown that race and racial segregation can constrain sexual networks, which can lead to fewer inter-racial sexual partnerships. In one study, researchers suggested that “...[b]ecause of racially segregated mixing patterns [the combination of sexual partners in any give subpopulation]...in African Americans, exposure to the virus is more likely among blacks than among whites for any given number of partners or frequency of sexual contacts.” Such social structures helped to constrain HIV-AIDS exposure among African Americans in areas where the disease was introduced, spread, and became endemic. Higher rates of poverty in communities of color also correlated with those sexual patterns.⁷⁸

The constraining of sexual networks also helps explain how mothers-to-be contracted the disease in Miami, which differed slightly from Newark and New York. In Miami, IV drug use was not as strongly correlated with higher rates of pediatric AIDS, even though evidence suggest that shooting galleries (“get-off” houses) existed in the city. Some evidence also suggests that HIV-AIDS was in Miami at least by 1978. According to Dr. Gwendolyn Scott — one of the early pediatricians who worked with pediatric AIDS patients — she saw her first case of pediatric AIDS in 1981. Those children, Scott, stated, were of Haitian decent. Unlike in the New York-metro region, the

⁷⁸ Adaora A. Adimora, Victor J. Schoenbach, and Michelle A. Floris-Moore. "Ending the epidemic of heterosexual HIV transmission among African Americans." *American Journal of Preventive Medicine* 37, no. 5 (2009): 468-471. Inter-racial sexual partners were also rare among black men who had sex with men. Hong-Van Tieu et al, "Sexual networks and HIV risk among black men who have sex with men in 6 US cities." *PloSone* 10, no. 8 (2015): e0134085.

gap between reported cases of transmission among IV drug users and through heterosexual contact in Miami was less wide. By the late 1980s, for example, reports indicated that roughly 15 percent of IV drug users had HIV-AIDS and 20 percent reported contracting the disease through heterosexual contact, which was five times the national average. Among Haitians, the vast majority of cases, 85 percent, were the result of heterosexual contact.⁷⁹ This is not to suggest that other women of color were not at greater risk of HIV-AIDS in South Florida: they were.⁸⁰ But the Miami experience underscores how the unequal distribution of pediatric AIDS was linked to the particularities of the socio-ecological conditions in which a mother-to-be lived — whether that was Little Haiti in Miami, the South Bronx, or Newark’s Central Ward.⁸¹

Similar Environments, Different Outcomes: Detroit

While disruptions in urban ecosystems helped facilitate the rise and concentration of pediatric AIDS in some U.S. cities, such phenomena did not always lead to higher rates of the disease among children in other places. In his book *The New American Ghetto* (1995), the renown photographer and visual chronicler of American urban decay, Camilo Jose Vergara, reminds us of the delapidated conditions found in once-thriving

⁷⁹ Dr. Gwendolyn Scott, interview by Gerald Oppenheimer, January 16, 1996 and January 17, 1997, transcript, Physicians and AIDS Oral History Project, Oral History Research Office, Columbia University Special Collections, New York, NY (hereafter cited; Scott oral history); “Case Study of Miami: AIDS Service Demonstration Project,” *Final Report*, June 27, 1989, Box 5, Folder “Transcripts of Briefings, Hearings and Meetings, 1989 - 1992, Florida Site Visit,” National Commission on Acquired Immune Deficiency Syndrome Records 1983 – 1994, History of Medicine Division, National Library of Medicine, Bethesda, MD (hereafter cited; National Commission Papers).

⁸⁰ Miami-Dade County, see: http://miamidade.floridahealth.gov/programs-and-services/infectious-disease-services/hiv-aids-services/_documents/hiv-surveillance-monthly-report-2016-06-B.pdf

⁸¹ My reference to and use of “socio-ecological” conditions in some cities is informed by the work of the social epidemiologist Nancy Krieger. See, for example: Nancy Krieger, *Epidemiology and the People’s Health: Theory and Context* (New York: Oxford University Press, 2014).

U.S. cities. From Gary, Indiana to East Los Angeles to Newark, Vergara reveals how the ruins in those cities are remarkably indistinguishable from one another, save for some recognizable landmarks.. Those “American ruins” were symbols and consequences of the same economic, social, and physical transformations that created the ecological conditions that concentrated pediatric AIDS in particular places.⁸²

Detroit, Michigan also experienced similar transformations in its social, economic, and urban landscapes. During the 1970s and 1980s, racial segregation worsened in Detroit, people of color in the city continued to be denied good employment, and poverty became increasingly concentrated in poor Black neighborhoods. For example, during this period, African Americans living in high-poverty areas of the city climbed from one-tenth of the population to one-fifth.⁸³ It is perhaps no surprise, given such conditions, that Detroit became a node in the national distribution of heroin. Like in New York City, Detroit saw the supply of heroin ebb and flow from the Second World War to around 1980. News reports from the late 1970s to the early 1980s ran headlines such as “Detroit Leads in Heroin Use” (1976) and “Detroit Ranks Second in U.S. Heroin Trade” (1982). Stories from the late 1970s pointed to the tens of thousands of heroin users in Detroit.⁸⁴

But Detroit did not see similar rates of HIV-AIDS among children and their families. In a National Institutes of Drug Abuse report title *Needle Sharing Among*

⁸² Camilo J. Vergara, *American Ruins* (New York : Monacelli Press, 1999).

⁸³ Sugrue, *The Origins of the Urban Crisis*, 269.

⁸⁴ Schneider, *Smack*; “Detroit Leads in Heroin Use,” *Chicago Tribune*, December 7, 1976; “Federal Study Hints Ratio of Heroin use in Detroit is Highest in the Country,” *The New York Times*, December 14, 1976; “Detroit Ranks Second in U.S. Heroin Trade,” *Washington Post*, November 2, 1982; Thomas Mieczkowski, “Street Selling Heroin: The Young Boys Technique in a Detroit Neighborhood” (Dissertation, Wayne State University, Detroit, MI, 1985).

Intravenous Drug Abusers (1988), Michigan did not rank in the top ten states with cases of HIV-AIDS among IV drug users in the United States by 1987. In fact, Detroit was not mentioned in the report (nor was Michigan). The absence of Detroit from the report, especially given the presence of heroin in that city by 1980s, suggests that patterns of syringe sharing were not a major vector for HIV — as was the case in cities where shooting galleries were frequented by IV drug users.⁸⁵ By 1988, moreover, Michigan and Detroit health officials reported relatively low numbers and rates of HIV-AIDS in general and among children specifically. The medical Director of Detroit’s Health Department, Virginia Y. Mesa, told Congress that there were 679 cases of HIV-AIDS in and around the city. The majority of cases were among men, with about 14 percent of all cases among women, 76 percent of whom were Black and reported acquiring the disease through IV drug use; 11 percent acquired it through heterosexual contact. Only seven children were reported to have acquired the disease perinatally by 1988. By contrast, the borough of Brooklyn alone reported 117 cases of pediatric AIDS by that same year.⁸⁶

⁸⁵ “Needle Sharing among Intravenous Drug Abusers,” 10. This does not suggest that Detroit did not have higher rates or cumulative cases of HIV-AIDS among adults and children, relative to other cities – they did. Looking forward to 2000, the CDC report roughly 7,736 cases of HIV-AIDS among adults and 73 cases among children under 13. Yet in that same surveillance report, the CDC reported that Baltimore had roughly 14,306 cases in adults and 208 in children. By all accounts, syringe sharing practices in Baltimore mirrored those in New York City and Washington D.C. The data about HIV-AIDS cases and rates is derived from: CDC, *HIV/AIDS Surveillance Report*, “U.S. HIV and AIDS cases report through December 2000, Year-end edition” 12, No. 2.

⁸⁶ “Testimony: Medical Director, Virginia Y. Mesa, Detroit Health Department”; “Testimony Michigan Department of Public Health,” April 24, 1989, “HIV infection in Detroit and Wayne County: Current status and Projections, in *The AIDS Epidemic in Newark and Detroit, Day 2, Hearings before the Human Resources and Intergovernmental Relations Subcommittee of the Committee on Government Operations*, 101th Cong. (1989). CDC, *HIV/AIDS Surveillance*, “AIDS cases reported through December 1988,” Issued January 1989; New York State Department of Health, “AIDS in New York State Through 1988.”

While Detroit is one counter example to the cities along the East Coast, it nevertheless reveals that some families were at higher risk of contracting HIV-AIDS. As we have seen, the unequal distribution of HIV-AIDS among certain families and communities was the result of the particular ecological conditions in those places. Those conditions were produced by urban policy decisions, racialized segregation, social dislocation, concentrated poverty, IV-drug-use patterns, and the arrival of HIV — all of which led to and contained pediatric AIDS in certain areas of the United States. This becomes important when exploring how pediatric AIDS gained greater public attention by the late 1980s and early 1990s. As we will see in chapter three, pediatric AIDS became part of the national conversation about urban poverty. Here, pediatric AIDS became synonymous with “the inner city,” a place many Americans understood to be “pathological.” But as the unequal geographic distribution of pediatric AIDS reveals, comprehending the rise and concentration of that disease phenomenon is not best understood by simply highlighting the “problems of the inner city.” We must, instead, look to how particular urban “ecologies of injustice” were not only formed and perpetuated, but how they also uniquely impacted families of color as HIV spread through those communities.

It was in those cities and communities where pediatric AIDS first became visible to health care and public health professionals. As healthcare workers in the U.S. began witnessing mysterious health problems in young gay men in the early 1980s, so too were some pediatric healthcare workers in the Bronx, Miami, and Newark. As the epicenters for HIV-AIDS in children and their families, the pediatric-healthcare professionals in those places thus became central figures in scientifically identifying the disease in

children; developing models of care; and in some cases, learning how to be public spokespeople for their patients and the problems they faced.

CHAPTER 2: “THE LITTLEST VICTIMS”: THE EMERGENCE OF PEDIATRIC AIDS AND ITS REPRESENTATIVES, 1967—1985

By the late 1970s and early 1980s, a few children in New York and Newark were experiencing unexplained health problems. Eve was one of those patients. Born in September 1979, Eve showed signs of developmental regression, and other health issues, at ten months old. As physicians tried to understand and treat Eve's peculiar health problems, the young patient died on May 29, 1981 from a rare form of pneumonia, *Pneumocystis carinii* pneumonia (PCP).⁸⁷ On June 5, 1981, a week after Eve's death, the CDC's *Morbidity and Mortality Weekly Report (MMWR)* published what became the first reported cases of AIDS. The five young, gay men from Los Angeles, who were featured in the *MMWR*, died from the same illness that killed Eve, although no one knew it at the time.⁸⁸

During the first few years of the epidemic, pediatric-healthcare workers in three U.S. cities began identifying and responding to the first cases of pediatric AIDS in the U.S. For those workers in New York City, Newark, and Miami, the emergence of this new disease presented them with a medical mystery and a shocking new problem they were unaccustomed to: a growing number of dying, pediatric patients. Historians have shown how physicians, specifically, not only responded to this new disease, but how the

⁸⁷ Patient record, “Eve,” Oleske Personal Papers.

⁸⁸ CDC, “*Pneumocystis* Pneumonia – Los Angeles” *Morbidity and Mortality Weekly Report (MMWR)*, 30, no 21 (June 5, 1981): 1-3. Pauline Thomas et al., “HIV Infection in Heterosexual Female Intravenous Drug Users in New York City, 1977-1980,” *The New England Journal of Medicine* 319, no. 6 (August 11, 1988): 374; D. Thomas, “Infants of Drug-Addicted Mothers,” *Australian Pediatric Journal* 24, no. 3 (June 1988): 167–68. As we saw in Chapter One, the first case of pediatric AIDS in the U.S. was retrospectively discovered in 1977.

crucible of the early AIDS epidemic also altered the careers of pediatricians in the U.S.,; transforming them into “AIDS doctors.” Scholars have also shown how similar experiences changed the careers of pediatric nurses, transforming them, too, into “AIDS nurses.”⁸⁹ Building on and moving beyond historical accounts about how the epidemic affected the career trajectories of many healthcare providers, this chapter focuses on how nurses, physicians, public health officials, public health workers, and the mass media all responded to the emergence of pediatric AIDS before 1985.

In order to capture the totality of these health care and cultural responses, this chapter follows the work of Dr. James Oleske. As a pediatrician working in Newark before the epidemic — coupled with his outsized role as a public, pediatric-AIDS representative — Oleske allows us to see how Americans began to recognize that AIDS was not just affecting and killing gay men during the early years of the epidemic. But this chapter is not a biographical sketch about how one physician rose to become an “AIDS doctor.” Instead, Oleske acts as a lens, our guide into how some Americans responded to the emergence of HIV-AIDS in children. Using the work of Oleske and others, we will see how the culture of post-World War II pediatric health care shaped the careers and clinical perspectives of those who first responded to AIDS in children; how health care and public health professionals developed early responses to the disease in children; and how people like Oleske tried to make visible the problem of pediatric AIDS within the growing public discourse about the epidemic.

⁸⁹ See, for example: Bayer, *AIDS Doctors*. Bayer and Oppenheimer do not discuss the work of “AIDS nurses” in their oral-history-based account of the AIDS epidemic before the year 2000. I am borrowing, however, the AIDS-doctor phrasing and applying to the other health care workers that were also responding to the epidemic.

Oleske, along with his cohort of pediatric-healthcare providers, entered the profession during the 1960s and 1970s. That era and culture of children's health care was marked by an increased focus on chronic-disease management, non-somatic child health issues, and better health outcomes for many children, which included a dramatic decrease in infectious disease-related deaths. When considering the changing landscape of pediatric health care, the 1960s and 1970s also saw the rise of the nurse practitioner, a new role in the profession of nursing. As hospitals in New York City, Miami, and Newark received more pediatric AIDS patients during the early 1980s, nurse practitioners, as well as other nurses, proved critical in the early history of pediatric AIDS — and beyond.⁹⁰ Regardless of training, nurses and physicians alike were transformed and disrupted by the emergence of AIDS, especially as the disease killed more of their patients. Physicians and nurses were certainly all affected by that disruption, but the nature and training of nursing, in particular, made them better prepared to cope with and manage a new, incurable infectious disease.

The work of nurses and physicians also reveals the initial difficulty healthcare professionals had in convincing others that AIDS was not just a disease of gay men. In 1983, clinical researchers working in Newark and the Bronx published the first case reports about AIDS in children; that is, children that contracted the disease through blood transfusions or tainted blood products.⁹¹ One of those researchers was Oleske, whose scientific conclusions became shrouded in controversy. As we move beyond that

⁹⁰ For the history of nurse practitioners, see: Fairman, *Making Room in the Clinic*. For the ways in which nurses responded to HIV-AIDS, see: McGarrah, *Transcending AIDS*.

⁹¹ By 1983, Dr. Arthur Ammann identified the first case of AIDS in children that received HIV-tainted blood. See, for example: A. J. Ammann, "Is There an Acquired Immune Deficiency Syndrome in Infants and Children?," *Pediatrics* 72, no. 3 (September 1983): 430–32; Ammann, *Lethal Decisions*.

controversy, we see how the epicenters of pediatric AIDS in the U.S. also produced the people responsible for the scientific knowledge, care models, and pediatric-AIDS-awareness raising that shaped how Americans came to understand HIV-AIDS in children in the years that followed.

Lacking a community of activists that could raise awareness about the problem of pediatric AIDS, children's health providers became the primary spokespeople for those children. Of course, the fact that they became public spokespeople for sick and dying children was not unique to the age of AIDS. Neither were some of the more potent strategies they used to call public attention to children born with the disease. While pediatric-healthcare workers lacked the large numbers of activists seen among gay-male AIDS organizations, we see, in the emergence of pediatric-AIDS advocacy, how a relatively small number of people were aided by — and used — the decades-old, “innocent victim” narrative in calling attention to what was also a relatively small population of AIDS sufferers. Oleske was one of those spokespeople calling attention to the “innocent victims” of AIDS. He also became the most vocal. As news media similarly began marginally reporting on pediatric AIDS, Oleske became a frequent voice candidly speaking about AIDS in children, urban poverty, and the need for more resources that he and his colleagues lacked.

While Oleske was representative of how pediatric-healthcare workers became spokespeople for pediatric AIDS, his outsized role in the public sphere is an important feature of pediatric-AIDS advocacy. Like his colleagues, he was called upon by journalists to provide medical information about AIDS in children, helped form state-level policy responses to the epidemic, and gave testimony to Congress. But unlike his

colleagues, Oleske's new-found role as an AIDS advocate was not merely a reaction to a disruptive new disease sickening and killing his pediatric patients. Rather, his relationship to, and work in, Newark profoundly shaped his career as an outspoken pediatric-AIDS advocate.

Most importantly, Oleske's role as a prominent pediatric-AIDS spokesperson reveals who became the representatives *for* children and families affected by the epidemic. When considering the emergence of such pediatric-AIDS advocates, we must place their work within the broader context of AIDS activism during this period. Gay-male AIDS activists were, in part, successful in raising awareness about the disease, and speaking truth to power, because they were not merely representing another group of Americans that were affected by and dying from AIDS. They *were* that group of Americans dying from the disease, vocal representatives that were the living embodiment of the AIDS epidemic among gay men.⁹² But unlike gay-male AIDS activists, pediatric-AIDS advocates were not representative of the communities they served. In this respect, their positions and power as spokespeople were the result of who they were *not*: residents of the poor, urban communities in which they worked. Their race, professional status, and social distance from the communities they served, helped make them into popular pediatric-AIDS spokespeople.

⁹² Information derived from: John-Manuel Andriote, *Victory Deferred: How AIDS Changed Gay Life in America* (Chicago: The University of Chicago Press, 1999); Epstein, *Impure Science*; Brier, *Infectious Ideas*.

Children's Health and Pediatric Healthcare before AIDS

The careers and cultures of pediatric-AIDS professionals were shaped by changes in children's health and health care that occurred decades before the epidemic began. From 1940 to 1980, overall rates in infant mortality dropped from 47 per 1000 births to 12.5.⁹³ Between these same years, children received greater access to vaccines and "magic bullet" cures such as penicillin.⁹⁴ Some historians of children's health posit that such technological advances and improvements in pediatric medicine alone helped bring about better health outcomes for children.⁹⁵ Others suggest that improvements in the standard of living, coupled with changes in medicine, helped in such outcomes.⁹⁶ Regardless, children's health outcomes improved in the years following World War II.

By the 1950s and beyond, the rate of deadly infectious disease also dropped in the United States. For many health professionals entering medicine in the late 1960s and early 1970s — which included many of the people that eventually cared for children with AIDS — the thought of confronting major infectious disease problems was perceived to be unfathomable. "Our generation came up in a time when infectious diseases were wiped out," Nurse Mary Boland explained, and with advancements in technologies like

⁹³ Children's Defense Fund (U.S.), *Black and White Children in America: Key Facts*. (Washington, D.C.: Children's Defense Fund, 1985). See also: Marilyn Irvin Holt, *Cold War Kids : Politics and Childhood in Postwar America, 1945-1960* (Lawrence: University Press of Kansas, 2014), 117–46; For history of childhood from the end of World War II to the 1980s, see: Steven Mintz, *Huck's Raft a History of American Childhood* (Cambridge, Mass. : Belknap Press of Harvard University Press, 2004.), 275–334.

⁹⁴ Bert Hansen, *Picturing Medical Progress from Pasteur to Polio: A History of Mass Media Images and Popular Attitudes in America* (New Brunswick: Rutgers University Press, 2009); Elena Conis, *Vaccine Nation : America's Changing Relationship with Immunization* (Chicago: University of Chicago Press, 2015); Arthur Allen, *Vaccine: The Controversial Story of Medicine's Greatest Lifesaver*, 1st ed. (New York : W.W. Norton, 2007).

⁹⁵ Stern and Markel, *Formative Years*.

⁹⁶ Dorothy Pawluch, *The New Pediatrics : A Profession in Transition* (Hawthorne, N.Y. : Aldine de Gruyter, 1996).

amniocentesis, child-healthcare healthcare professionals saw less congenital abnormalities.⁹⁷

The American public witnessed that shift in children's health outcomes as well. New medical technologies and therapies demonstrated to many in the U.S. that biomedicine in the mid-twentieth century could prevent, and potentially cure, a myriad of illnesses and conditions. For American parents, advances in biomedicine were made real in a number of ways, no more evident than in the development of the polio vaccine in the mid-1950s. By the 1960s, diseases that once affected and sickened children for decades — measles, mumps, and rubella, for example — were also prevented through the development of vaccines.⁹⁸ As infectious diseases and death rates of newborn children dropped, other diseases like cancer and cystic fibrosis garnered more attention, leading to a shift in pediatric-healthcare delivery.

After the 1950s, pediatric-healthcare professionals also shifted their focus towards other health-related issues. They include bedwetting, sleeping and eating disorders, nightmares, nervous tics, and even phobias.⁹⁹ That shift in professional focus also included an emphasis on a number of other related issues ranging from childhood behavioral issues and academic performance, to problems related to poverty, and single-

⁹⁷ Nurse Mary Boland DrPH, RN, FAAN, interview by Jason M. Chernesky, May 16 and 17, 2017 (hereafter cited; Boland oral history).

⁹⁸ Hansen, *Picturing Medical Progress from Pasteur to Polio*; David M. Oshinsky, *Polio: An American Story* (New York: Oxford University Press, 2005); Allen, *Vaccine*; Leslie J. Reagan, *Dangerous Pregnancies: Mothers, Disabilities, and Abortion in Modern America* (Berkeley: University of California Press, 2010); Jane S. Smith, *Patenting the Sun: Polio and the Salk Vaccine*, 1st ed. (New York: W. Morrow, 1990).

⁹⁹ Stern and Markel, *Formative Years*; I. B. Pless, "The Changing Face of Primary Pediatrics," *Pediatric Clinics of North America* 21, no. 1 (February 1974): 223–44; Robert J. Haggerty, *Child Health and the Community* (New York: Wiley, 1975); Pawluch, *The New Pediatrics*, 1.

parent households — all of which, by the 1970s, came to be known by pediatric-health experts as the "new morbidity" of children's health.¹⁰⁰

As pediatric health care broadened its focus, incorporating more non-somatic disease conditions into its professional purview, pediatrics saw a rash of sub-specialization. Between the 1960s and 1970s, pediatricians took on "particular problem areas," such as epilepsy, hormonal disorders, and heart conditions. Those same years saw the rise of pediatric hematology and oncology, neonatal and perinatal medicine, nephrology, endocrinology, immunology, as well as allergy and infectious disease specialists.¹⁰¹

The pediatric health care experts who isolated the first cases of pediatric AIDS were products of those changes in pediatrics and children's health. Entering medical school during the 1960s, Arye Rubinstein was attracted to caring for children and the science of immunology, which was still a relatively new subfield in pediatrics during the 1960s and 1970s.¹⁰² Rubinstein realized his passion for immunology while attending medical school in Bern, Switzerland. "The immune system is...the gatekeeper," he remarked, "between us as individuals, between us and the outside world. It defines us as a microcosm in the macrocosm."¹⁰³ While at Albert Einstein Medical School in the 1970s,

¹⁰⁰ Haggerty, *Child Health and the Community*, 2.

¹⁰¹ Pawluch, *The New Pediatrics*, 34; Sydney A. Halpern, *American Pediatrics : The Social Dynamics of Professionalism, 1880-1980* / (Berkeley : University of California Press, 1988.), 111.

¹⁰² Dr. Arye Rubinstein, interview by Gerald Oppenheimer, February 8, 1996, transcript, Physicians and AIDS Oral History Project, Oral History Research Office, Columbia University Special Collections, New York, NY (hereafter cited; Rubinstein oral history. For history of pediatric immunology, see Arthur M. Silverstein, *A History of Immunology*, 2nd ed. (Amsterdam ; Academic Press/Elsevier, 2009), 402–7.

¹⁰³ Rubinstein oral history

Rubinstein not only continued pursuing his passion for immunology, but he also became an established immunology researcher.¹⁰⁴

Oleske was also drawn to immunology. A native of New Jersey, Oleske attended medical school in New Jersey, where he graduated in early 1970s. After finishing a fellowship in Atlanta — working at Emory University as well as the CDC — he returned to Newark in 1976 with the intention of setting up a "state-of-the art" immunology, infectious disease, and allergy training program.¹⁰⁵

A love for microbiology helped influence Gwendolyn Scott's professional trajectory during the mid-1970s. A graduate of the University of California – San Francisco (UCSF) Medical School, Scott, while completing her residency in Baltimore, said that she recognized her “love for...laboratory microbiology." Shaped by that experience, Scott pursued a career as a pediatric-infectious-disease specialist, eventually moving to Miami after her husband, a biochemist, took a job at the University of Miami.¹⁰⁶

The changes in pediatric health care that shaped the career trajectories of physicians like Oleske, Rubinstein, and Scott, influenced nurses as well. A native of Philadelphia, Nurse Mary Boland graduated from Temple University's nursing diploma program in the

¹⁰⁴ The following is a selection of Rubinstein's research before his role as HIV-AIDS scientist: Arye Rubinstein, et al., "Successful Bone-Marrow Transplantation in a Lymphopenic Immunologic Deficiency Syndrome," *The New England Journal of Medicine* 285, no. 25 (December 16, 1971): 1399–1402; Arye Rubinstein et al., "Possible Effect of Maternal Promethazine Therapy on Neonatal Immunologic Functions," *The Journal of Pediatrics* 89, no. 1 (July 1, 1976): 136–38; Arye Rubinstein et al., "Comparative Analysis of Systemic Immunological Parameters in Ulcerative Colitis and Idiopathic Proctitis: Effects of Sulfasalazine in Vivo and in Vitro," *Clinical and Experimental Immunology* 33, no. 2 (August 1978): 217–24.

¹⁰⁵ Dr. James M Oleske, interviewers Barbara S. Irwin and Robert B. Burnett, transcript, July 28, 1994, New Jersey AIDS Oral History Program, Rutgers University Health Sciences Special Collections in the History of Medicine, Newark, NJ, (hereafter cited; Oleske oral history, Rutgers University), 2.

¹⁰⁶ Scott oral history, 6-7; quote derived from pg. 6..

early 1970s. Attracted to the popular subfield of pediatric nursing, Boland took a position at St. Christopher Children's Hospital in Philadelphia immediately after leaving Temple. Of the two positions open at the time, Boland took the one in the neonatal intensive care unit (NICU), which was the result of her telling the Director of Nursing she wanted a position where she could learn and grow professionally. The NICU was a relatively new feature in pediatric hospitals, and working in the units required nurses to be technologically proficient. Boland's desire for professional growth and intellectual challenges pushed her to complete a bachelor's degree in nursing at the University of Pennsylvania in the mid-1970s. In part, her completion of the bachelor's degree was driven by her desire to become a nurse practitioner (NP), also a new role in nursing at the time. She wanted to be an NP because of "the autonomy in the role...the ability to keep growing and keep learning...not to be doing the same things all the time."¹⁰⁷

Changes to health care practice and funding during the 1960s and 1970s helped facilitate the rise of the NP. At the time, nurses and physicians were undergoing a professional identity crisis. Physicians were confronted with larger patient loads, a decrease in primary care doctors, and a flood of clinical information with the rise of new medical technologies. Meanwhile, some nurses became frustrated with the limitations of practice that were, in part, structured by the professional boundaries that separated the work of physicians and nurses. Within that context, nurses negotiated a space in the American health care left open by the growing need for general practitioners. In an era

¹⁰⁷ Boland oral history. See also: Nurse Mary Boland's Curriculum Vitae/Biographical Sketch, Box 3, Folder 9, New Jersey AIDS Collection, Rutgers Special Collections in the History of Medicine, Newark, NJ (hereafter cited; NJ AIDS Collection). From 1970 through 1975, prior before becoming an NP Boland worked as a staff nurse and head nurse at St. Christopher's Hospital in Philadelphia; as an instructor at Fairleigh Dickinson University in New Jersey; and finally working in Newark around 1979. As the AIDS epidemic emerged in 1981, she was an NP at Children's Hospital in Newark.

that saw more access to health care among the poor and elderly due to the introduction of Medicare and Medicaid, nurses found the NP role as a way to use their knowledge and skills to provide clinical care to patients once under the purview of physicians¹⁰⁸

By the time Boland wanted to become an NP in 1975, there were only a few master's degree programs in the country. Wanting to be close to New York City for her husband's career, she chose the only one in that area at the time: the NP program at Seton Hall University in South Orange, New Jersey. While working on her master's degree, Boland also taught nurses, part-time, at University of Medicine and Dentistry of New Jersey (UMDNJ) in Newark. After taking a few teaching positions and some clinical work in and around Newark, Boland was eventually recruited to work at the Children's Hospital's NICU in Newark in 1981. The AIDS epidemic had just begun, and during those first few years the disease did not organically find its way into her professional life the way it did Oleske's, Scott's, or Rubinstein's; that is, she was not yet presented with children suffering from a mysterious set of health conditions. Nevertheless, while Boland found work at Children's Hospital's NICU — where Oleske would eventually find her — she was not initially attracted to Newark because of her initial experiences training and working there as an NP.¹⁰⁹ That was different for Oleske. His professional life was profoundly shaped by the city of Newark during the late 1960s and early 1970s.

¹⁰⁸ Fairman, *Making Room in the Clinic*, 1–20.

¹⁰⁹ Boland oral history.

The Power of Place and Its People

In 1967, Oleske entered the New Jersey College of Medicine and Dentistry (NJCMD) at a time when the school became a political flashpoint between city officials and Newark residents. In 1966, city officials in Newark began planning a massive urban-renewal project: the construction of a new site for the medical school and its hospital. The initial plans called for the use of a one-hundred-and-fifty-acre plot of land in the city's Central Ward, which would displace the residents living in that part of Newark. The planned construction of the academic medical center and hospital not only became a contentious urban renewal issue among the city's residents: it also became one of the many underlying causes that led to the violent uprising in Newark during the summer of 1967.¹¹⁰

After the uprising in Newark — a phenomenon that occurred in many other U.S. cities in the late 1960s — the planned construction of the academic medical center and hospital began to change. City officials and the medical school leadership began listening to the demands of community advocates in Newark. Through a set of negotiations, community advocates successfully helped establish an agreement between the medical school and the city's residents that ensured the school addressed issues of employment, fair admitting practices, the health care needs of the community, and housing. The

¹¹⁰ A number of scholars have discussed the causes and consequences of the 1967 uprising in Newark during the summer of 1967. The following are two recent examples. Rabig, *The Fixers*, 69–96; Krasovic, *The Newark Frontier*, 127-179.

community-advocate-backed initiative also led to the reduction in land that was eventually used for the school's new location in Newark, just over fifty acres.¹¹¹

For many Americans, the uprisings of 1967 revealed the serious problems affecting poor urban areas that were largely unnoticed or ignored by those living outside such places. The inadequate health care and the poor health of people of color in the U.S. were just two such revelations. The rediscovery of poverty, as well as new problems facing populations of color, became the focus of national health care leaders. In 1969, healthcare professionals, students, scholars, elected officials, and many others held a conference in New Hampshire titled *Medicine in the Ghetto*, at which they discussed the various problems facing health care in America's poorer cities and neighborhoods. Health care delivery in Newark was a topic of discussion at the conference.¹¹²

The politics of urban upheaval, the health problems of the poor, and the culture of the 1960s undoubtedly also influenced the cohort of medical school students entering the NJCMD during that time. In a NJCMD periodical titled *Contrast*, [Images 1 and 2] medical students voiced their frustrations about what they witnessed while training in Newark. In a 1968 piece titled "Newark," one student wrote that the city seemed to have been "passed over by the pretty sunshine rays that grow green grass in Glenridge [an affluent suburb]; only the burning rays strike Newark." He spoke of the high TB rates in the city and the problem of drug use among some of the city's residents. The

¹¹¹ Rabig, *The Fixers* and Krasovic, *The Newark Frontier*.; Reference to civil unrest in other cities is derived from: National Advisory Commission on Civil Disorders, *Report of the National Advisory Commission on Civil Disorders* (Washington, D.C.: G.P.O., 1968).

¹¹² The health and health care of poor urban communities was part of the national commission that published a report about the uprisings: United States. National Advisory Commission *Report on the National Advisory Commission on Civil Disorders*; Beverly Bennett and John C. Norman, eds. *Medicine in the Ghetto*. (New York: Appleton-Century-Crofts, 1969).

unemployment that awaited African Americans who migrated to the city from the South, coupled with “emotional and psychological burden[s]” of poverty were just a few of the social problems the student saw as in desperate need of attention. Speaking to his fellow students and health care professionals, the author wrote that “[t]hese social...problems must be considered in the overall planning for health services.”¹¹³

Besides channeling a decades-old social-medicine perspective, students also opined about their position as healthcare professionals in a poor, urban environment. In 1969, another student wrote an article titled, “The Realities of Ghetto Medicine” in which he tried to convey to colleagues that the “hostile” patients they encountered during their training were byproducts of a set of difficult social and environmental circumstances. Their lives, he wrote, were overburden by “discrimination, poverty, unemployment and frustration.” The physician and hospital — specifically Martland Hospital, the city hospital where the students trained, which was also known as “The Slaughterhouse on 12th Avenue” — was to patients “just an extension of the same rotten outside world.” The author ultimately wanted to remind his fellow students to engage their patients with a degree of empathy regarding their socio-economic problems, and to enter the hospital with a sense of humility and perspective. “Maybe a mother is impressed by her son the medical student” in his freshly starched “whites,” he wrote, “but to the patients, [a] physician’s ‘whites’ are as frightening as policemen’s ‘blues.’”¹¹⁴

¹¹³ Dan Tartaglia, “Newark” *Contrast*, 1968 [no month], New Jersey Medical School Collection, RG/D-1, Box 2b, Folder 5, *Contrast* 1968-1969, Rutgers University Medical Library Special Collections, Newark, NJ (hereafter cited; NJ Medical School Collection).

¹¹⁴ Joseph R. Martire, “The Realities of Ghetto Medicine,” *Contrast*, March 1969, RG/D-1, Box 2b, Folder 5, *Contrast* 1968-1969, NJ Medical School Collection.

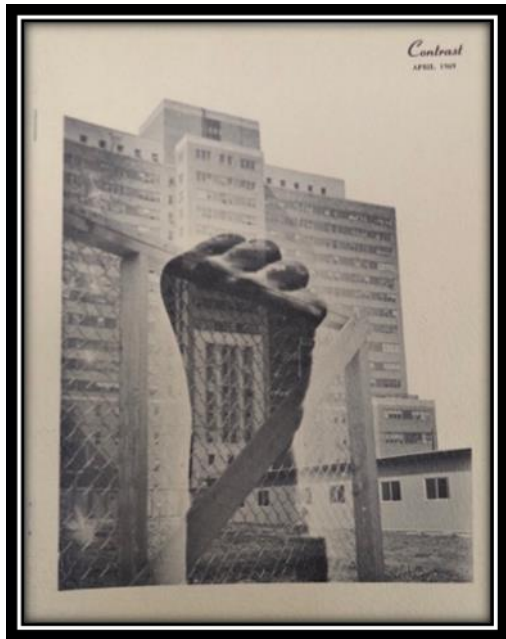


Image 1: *Contrast Magazine*, April 1968
Source: Rutgers Medical Library Special Collections
Note: Martland Hospital is in the background



Image 2: *Contrast Magazine*, March 1968
Source: Rutgers Medical Library Special Collections

Within that context, Oleske was acculturated into the healthcare profession. He also seemed to embrace the spirit of the age. Besides writing satirical articles and poetry for *Contrast*, he used the publication to promote the Family Health Care Center (FHCC) where he volunteered. He wrote: "The central Ward, soon to be the home of N.J.C.M has many sick, tired families who require more than a [day's] wait at a clinic for a brief examination." What seemed to be a free, volunteer-run clinic, the FHCC was established, he mentioned, to provide "services" — no details about what kind of services — to families in the city, and that volunteering at the clinic exposed students to "family-doctor relationship experience not available elsewhere."¹¹⁵ Years later, Oleske recalled

¹¹⁵ The quotes and Oleske's writing about the Family Health Center is from: James Oleske, "Family Health Care Center," *Contrast* 1968 [no month]; for his other writings in *Contrast*, see: "The Education of the

that the clinic was run by a group called the Student Health Organization. More importantly, the experience made him aware of, and provided him knowledge about, “how difficult it was for women with kids, living in poverty.” That experience was part of the post-uprising era in Newark that helped shape his career, Oleske remembered. “Like a lot of kids at that time,” he said, “after the riots, it was a spirit of let’s stay in Newark and make this a good school and make our alma mater proud...I, with a lot of other people...stayed on as an intern and then resident in pediatrics at Martland Hospital.”¹¹⁶ What is unclear from Oleske’s early writings and later remembrances was whether he was also influenced by larger national discussions about the health of American children, especially children of color.

Though the vast majority of American children were healthier by the 1970s, some child-health advocates nonetheless continued discussing how health inequalities were affecting poor children in the U.S. In 1970, the Russian-born pediatrician Max Seham wrote in *Pediatrics* that “our privileged children have access to the best medical care in the world, but the poor 'kids' get only crumbs of what technology has to offer.” He said that we needed “a frontal attack on poverty and its associated evils,” not more conferences and basic research.¹¹⁷ In a shift from their 1960 conference, the White House Conference on Children in 1970 focused more on the racial and economic inequities that affected the health of poor children. They were even quite pointed in their assessment

Doctor,” *Contrast* April 1969; “Confessions of an Addict, *Contrast* June 1969, RG/D-1, Box 2b, Folder 5, *Contrast* 1968-1969, NJ Medical School Collection.

¹¹⁶ Dr. James Oleske Oral History, Interviewed by Ronald Bayer, March 4, 1995 and September 19, 1996, transcript, Physicians and AIDS Oral History Project, Oral History Research Office, Columbia University Special Collections, New York, NY (hereafter cited; Oleske oral history Columbia).

¹¹⁷ Max Seham, “Poverty, Illness, and the Negro Child,” *Pediatrics*, 46, no. 2, (August 1970): 305-311; quote derived from 310.

about the effects of race, stating that “[r]acism is the most threatening social disease in this country.”¹¹⁸ Through the 1970s and into the 1980s, the Children’s Defense Fund highlighted those racial disparities as well. One report showed that six out of ten Black children were born to mothers who did not receive prenatal care; Black children were twice as likely to die in infancy than white children; and diseases closely associated with poverty, such as TB, were four to five times higher in Black children than white children.¹¹⁹ Some of those statistics, especially the higher rates of infant mortality, would have been familiar to health care professionals working in Newark during that time.¹²⁰

It is unlikely that such national conversations and concerns about health inequalities did not directly influenced Oleske’s decision to return to Newark after graduating medical school. Nevertheless, he returned to Newark in 1976 “with great hopes of setting up a state-of-the-art immunology, infectious disease, allergy training program so that kids in Newark and families in New Jersey would have access to state-of-the-art care.” He did not set up a training facility, but he worked in Newark for the remainder of his career.¹²¹

While working in Newark during the late 1970s, he provided some evidence that foreshadowed future claims that pediatricians were the most effective spokespeople for

¹¹⁸ In 1960, the conference did not spend significant time discussing issues of poverty and health: see, Eli Ginzberg, *Committee on Studies for the Golden Anniversary White House Conference for Children and Youth*. (New York : Columbia University Press, 1960); *Report to the President -- White House Conference on Children*. (Washington: G.P.O, 1971); quote derived from 160.

¹¹⁹ Children’s Defense Fund, *Black and White Children in America: Key Facts* (Washington DC: Children's Defense Fund, 1985).

¹²⁰ Robert S. Powell, Jr. et al, “The Doctor is Out...A Report on The Newark, New Jersey Division of Health,” The Center for Analysis of Public Issues, 1972, Rutgers University Special Collections Medical Library.

¹²¹ James M. Oleske Biographical Sketch, National Pediatric HIV Resource Center, grant proposal, Box 3, Folder 9, NJ AIDS Collection; Oleske oral history, Rutgers University, 4.

underprivileged children. In 1977 he published an article in *Clinical Pediatrics* about heroin withdrawal symptoms among 118 children born to mothers that were drug users. In his concluding remarks, he wrote that "[t]he pediatrician has always been the professional spokesman for the silent victims of our society's mishaps. This role, thus, must not end with the discharge of the newborn — every effort must be extended to improve and maintain the health of these infants who are brought into this world in such adverse circumstances."¹²² Oleske would later use this type of rhetoric when advocating for pediatric AIDS patients in the early years of the epidemic.

When Oleske suggested that pediatricians were the spokespeople of the "silent victims" of "society's mishaps" in the 1970s, he echoed the concerns of his contemporaries and earlier child-health advocates. But he was not a pediatric-health professional working with disease foundations, policy institutes, or other similar groups attempting to address health inequalities. Such commentary was not normally found in clinical reports. The 1977 article was not primarily about, nor a call for, the importance of the pediatric-health professional's role as a spokesperson for the "innocent victims" of disease and related social problems. Nor was the article about how race, poverty, or America's lack of a comprehensive health system for children conspired to affect the 118 children in his study.¹²³ Rather, it was a fairly conventional descriptive report of a clinical phenomenon in a specific biomedical trade journal. What Oleske's commentary reveals, though, is how references to the innocent victimhood of sick or at-risk children had

¹²² James Oleske, "Experiences with 118 Infants Born to Narcotic-Using Mothers. Does a Lowered Serum-Ionized Calcium Level Contribute to the Symptoms of Withdrawal?," *Clinical Pediatrics* 16, no. 5 (May 1977): 422–23. Information about the long tradition of "innocent victimhood" is derived from: Viviana A. Rotman Zelizer, *Pricing the Priceless Child: The Changing Social Value of Children* (New York: Basic Books, 1985).

¹²³ Oleske, "Experiences with 118 Infants Born to Narcotic-Using Mothers."

become a normalized rhetorical device among some child-health professionals. That language remained a rhetorical strategy for Oleske and others as they tried to call attention to the problem of pediatric AIDS in the early 1980s.

Most importantly, while Oleske's medical school experience in Newark impacted how he approached pediatric health care, his impulse to stay in Newark, and make his "alma mater proud," was not merely the direct result of his progressive idealism. Oleske took seriously the 1968 Medical College Agreement forged between the city, the medical school, and a cadre of mostly Black activists in Newark. Among the many details put forth in the agreement was the city's and school's promise to provide better healthcare services to the residents of Newark. There could not be "genuine progress," the document read, "without medicine making its boldest commitment."¹²⁴ That agreement, what some have called the "Magna Carta" of post-uprising Newark, was not simply a consequence of legal battles or banal political processes; it was, as the historian Julia Rabig argued, "forged in blood and fire." The agreement was the direct consequence of the 1967 uprising and the subsequent negotiations that were led by local activists and community leaders.¹²⁵ Oleske's pediatric-AIDS advocacy was a direct result of those events and those activists that forced the medical school and its people to live up to the promises printed in the Medical College Agreement.

¹²⁴ "Agreements Reached Between Community and Government Negotiators Regarding New Jersey College of Medicine and Dentistry and Related Matters," Oleske's personal copy, Oleske Personal Papers

¹²⁵ Rabig, *The Fixers*, 94.

The Emergence of Pediatric AIDS and Scientific Controversy

It is difficult to discern which physician saw the first cases of perinatally transmitted AIDS. Both Oleske and Rubinstein recall that they started to witness odd health problems in their patients between 1978 and 1981.¹²⁶ During those years, Oleske suggested, "it was clear that something was happening in our community. We were seeing isolated but increasing numbers of children who had very unusual immunodeficiencies."¹²⁷ Scott saw her first cases of what became AIDS in two Haitian children in 1981.¹²⁸

At that point, Oleske and Rubinstein began investigating and preparing reports of what they were witnessing in Newark and the Bronx. In the meantime, in December of 1982, the CDC published an *MMWR* title "unexplained immunodeficiency and Opportunistic Infections in Infants – New York, New Jersey, and California." All of the cases reported in the *MMWR* were children either born to IV drug abusers or were of Haitian decent. It was important for the CDC to point out that those children did not receive blood transfusions or use blood products.¹²⁹ In 1982, top CDC investigators were convinced that the new disease they were tracking was blood-borne, due in part to the suspected cases in people with hemophilia.¹³⁰ Though the children demonstrated similar

¹²⁶ Bayer and Oppenheimer, *AIDS Doctors*, 30-31; see also Dr. Rubinstein oral history.

¹²⁷ Oleske oral history, Rutgers University

¹²⁸ Scott oral history 16-17; Bayer Oppenheimer, *AIDS Doctors*, 30-31.

¹²⁹ CDC, "Unexplained Immunodeficiency and Opportunistic Infections in Infants--New York, New Jersey, California," *MMWR* 31, no. 49 (December 17, 1982): 665–67; for Arthur Ammann's role in identifying one of the first children with HIV-AIDS, which was the result of HIV-contaminated blood, see Arthur J. Ammann, *Lethal Decisions*.

¹³⁰ Pemberton, *The Bleeding Disease*, 244–45.

symptoms and illnesses that occurred in adult patients with AIDS, the medical and public health communities were still largely unconvinced that the children had AIDS.

One reason biomedical scientists and public-health experts were reluctant to accept that children could acquire AIDS was due to the quick acceptance that the new disease was associated with gay men. In 1981, as more cases of the disease were reported, the medical community called it Gay Related Immune Deficiency (GRID). Because of the stigma attached to the name, and the fact that it did not accurately capture the various other people — specifically Haitians, hemophiliacs, and IV drug users — diagnosed with the disease, it was changed to AIDS by 1982.¹³¹

But the framing of AIDS as "gay disease" stuck, and the power of this framing influenced how some medical scientists and public health professionals first interpreted what Oleske and Rubinstein witnessed in their patients. Jim Curran at the CDC told Rubinstein that "Arye, what am I going to do? I'm convinced that [what you're seeing] is pediatric AIDS, but no one in a sane mind will accept it."¹³² The reviews of an abstract Oleske submitted for publication suggested that what he was seeing was another immunodeficiency, Nezelof's syndrome. "I couldn't believe they'd rather think we're having an epidemic of [an]...inherited immune deficiency syndrome," Oleske claimed.

¹³¹ Allan M. Brandt, *No Magic Bullet: A Social History of Venereal Disease in the United States Since 1880*, Expanded Edition (New York: Oxford University Press, 1987), 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*.

¹³² See, Bayer, *AIDS Doctors*, 30; see also Rubinstein oral history 39.

He was confident his patients had AIDS, "but no one wanted to believe it."¹³³ In his book *And the Band Played On* (1987), Randy Shilts wrote about how Rubinstein's article had been rejected from the *New England Journal of Medicine* in 1982, claiming that the reviewers made a "firm conclusion that [those] kids most certainly did not have AIDS, the homosexuals' disease."¹³⁴

Others posited that the early reluctance in accepting pediatric AIDS was the result of scientific elitism. Boland witnessed "a lot of resistance" to the early reports of pediatric AIDS, and charges that physicians like Oleske were just "grand standing...trying to make a name for yourselves." She claimed how "the traditional Ivy League" infectious disease and immunology experts thought "this is ridiculous. There's nothing there" — that is, because, such clinical reports did not emanate from medical schools and hospitals universally understood by biomedical researchers as top-tier institutions.¹³⁵ It is unclear whether Rubinstein or his colleagues had a similar perspective about their work. Although Albert Einstein College of Medicine was a more widely known and respected biomedical institution than UMDNJ Newark, Rubinstein also faced opposition by the biomedical community when he first hypothesized that children in the Bronx had AIDS.

Though Oleske and Rubinstein initially struggled to have their findings accepted, their work was eventually published in the *Journal of the American Medical Association* (*JAMA*) on May 5, 1983. Rubinstein's article, "Acquired Immunodeficiency with reversed

¹³³ Information and quote derived from Bayer, *AIDS Doctors*, 31; Dr. Oleske also mentioned that he first presented his findings at the American Academy of Allergy and Immunology meeting in 1982; this is derived from Oleske oral history, Columbia. Information about framing disease is derived from Charles E. Rosenberg, "Framing Disease: Illness, Society, and History," in Charles E. Rosenberg, Janet Lynne Golden, and Francis Clark Wood Institute for the History of Medicine, eds., *Framing Disease: Studies in Cultural History* (New Brunswick, N.J: Rutgers University Press, 1992).

¹³⁴ Randy Shilts, *And the Band Played on*; quote derived from, 172; see also 104.

¹³⁵ Boland oral history

T4/T8 Infants born to Promiscuous and Drug-addicted Mothers," presented seven case studies of children that showed signs of AIDS. Rubinstein and his colleagues suggested that AIDS was perhaps vertically transmitted from mother to child.¹³⁶ Oleske and colleagues made similar observations but concluded that the child's household exposure with adults may have contributed to them contracting AIDS. Detailing eight case studies, Oleske suggested that it was difficult to conclude whether the illness was due to a "sudden upsurge in congenital immune defects or congenital viral infections of the unusual type." Instead, it seemed plausible to Oleske, and his team, that "the illness in the youngsters were related in some way to household exposure and their residence in the communities involved in the current AIDS epidemic."¹³⁷

The finding immediately made headlines. The wire service, *UPI*, ran a story titled "Household Contact may Transmit AIDS." *NBC* and *ABC* nightly news broadcasts, as well as the *New York Times*, all reported that Oleske's case report suggested how AIDS could be transmitted through close contact in the household. Much of the media frenzy surrounding the study was also compounded by an editorial that Dr. Anthony Fauci, then a biomedical, infectious-disease researcher at the NIH, wrote in the same May 6, 1983 edition of *JAMA*. In it, Fauci suggested that the findings of AIDS in children had "enormous implications with regard to ultimate transmissibility of this syndrome." He qualified the statement, writing that "it is possible that AIDS can be vertically transmitted," but "even more important is the possibility that routine close contact, as

¹³⁶ Arye Rubinstein et al., "Acquired Immunodeficiency with Reversed T4/T8 Ratios in Infants Born to Promiscuous and Drug-Addicted Mothers," *JAMA* 249, no. 17 (May 6, 1983): 2350–56.

¹³⁷ James Oleske et al., "Immune Deficiency Syndrome in Children," *JAMA* 249, no. 17 (May 6, 1983): 2345-2349; quote derived from 2348.

within a family household, can spread the disease. If indeed the latter is true, then AIDS takes on an entirely new dimension."¹³⁸ Fauci's comment about "routine close contact" was quoted in the *New York Times* article about Oleske's study.¹³⁹

Some news organizations and periodicals had a more measured or critical take on the presumption of AIDS transmitted through casual contact. The *Miami Herald*, citing Dr. Harold Jaffe at the CDC, wrote that Oleske's study was controversial and that it left a number of questions unanswered about the transmission of AIDS before or during birth. Gay communities in the U.S. — concerned with any suggestion that the disease could be transmitted casually given the stigma placed on gay men since the beginning of the epidemic — were critical of Oleske's conclusions. In an article titled "New Studies Further Speculation on AIDS," *Gay Community News* in Boston interviewed a doctor that took issue with Oleske's findings and it provided a summary of Rubinstein's article that suggested how AIDS could be vertically transmitted from mother to child.¹⁴⁰

One of the most critical assessments of Oleske's article, and of the inability of major scientific institutions to effectively communicate the science of AIDS to the public, came from the science journalist Robert Bazell. In his essay, which appeared in the *New Republic*, he argued that certain types of reporting, and what he considered poor science, could have a negative impact on public perceptions of AIDS. He credited Oleske's article

¹³⁸ Sharon Rutenberg, "Household contact may transmit AIDS," *UPI*, May 5, 1983. Roger Mudd (broadcaster), *NBC Evening News*, May 5, 1983, VTNA. All material from the VTNA was digitally accessed through University of Pennsylvania Libraries; Max Robinson, *ABC Evening News*, May 5, 1983, VTNA. Quotes derived from, Anthony Fauci, "The Acquired Immune Deficiency Syndrome: the ever-broadening clinical spectrum," *JAMA* 249, no. 17 (May 6, 1983): 2375-2376.

¹³⁹ "Family Contact Studied in Transmitting AIDS," *New York Times*, May 6, 1983.

¹³⁹ Larry Goldsmith, "New Studies further Speculation on AIDS," *Gay Community News*, Boston, 10, Iss. 43, (May 21, 1983).

¹⁴⁰ Goldsmith, "New Studies further Speculation on AIDS."

in *JAMA* for creating an upsurge in hysteria about the supposed casual transmission of the disease. Asserting that institutions, such as the NIH, failed to provide sound scientific information to the public about AIDS, Bazell suggested that such failures resulted in "the gap [being] filled by scientists...like Dr. James Oleske of the New Jersey School of Medicine and Dentistry in Newark," an academic medical center, that was, in Bazell's words, "below the top rung." Bazell also claimed that "several scientists say Oleske's work is flawed (As Dr. Arye Rubinstein...diplomatically put it, 'My feeling was that the information included in his *JAMA* paper does not yet justify the far-reaching conclusion that there is an intrafamilial spread through casual contact')." According to Bazell, Oleske was "the first — and to my knowledge the only — scientist to claim that AIDS can be spread by casual contact."¹⁴¹

The criticism of Oleske's study, and the news coverage that followed, was an understandable consequence given the politically charged nature of the AIDS epidemic in 1983. Groups like the Gay Men's Health Crisis (GMHC), for example, were already active in criticizing local and federal governmental leaders about their slow response to the epidemic. Gay Activist and former owner of a San Francisco-area gay newspaper, Chuck Norris (not the actor), thought the news coverage about AIDS by 1983 tended to be sensational, focusing too heavily on the gay lifestyle rather than how the disease was destroying lives. In fact, by the spring of 1983, there was an uptick in news coverage about AIDS evidenced by a story airing on *20/20* — a popular news program — about

¹⁴¹ Robert Bazell, "An Epidemic of Myths and Misperceptions: The History of an Epidemic," *The New Republic*, August 1, 1983. Rubenstein also discusses Oleske's 1983 article and comments about casual contact, see: Rubenstein oral history.

the disease, a cover story about the disease in *Newsweek*, and the intense coverage Oleske's study received in the press.¹⁴²

Although much of that press coverage subsided through 1984, gay men were understandably frustrated with the negative or superficial stories that contributed to the growing stigma surrounding the disease and gay men. That made Oleske's study troubling for gay men. In 1987, Shilts called Oleske's findings and analysis "specious" and that his study, coupled with Fauci's comments, "lent scientific credibility to ungrounded fears" about how the disease was contracted. Those fears, Shilts argued, "would linger for years," and that the fear "inspired by this one story defined the context within which AIDS was discussed for the next crucial months."¹⁴³ It is difficult to ascertain whether the lingering public fears of casually contacting AIDS were the result of Oleske's study. But the spike in news coverage, albeit short-lived, may have alerted more Americans to the disease¹⁴⁴

Stories about Oleske's close-contact hypothesis also represented how sensational news accounts amplified fears about the "casual" acquisition of AIDS. Oleske may have unintentionally provided scientific credibility to fears that this new infectious disease could have been transmitted through close contact. But news stories also presented the information in a sensational and superficial manner, not uncommon for some news

¹⁴² *Inside Story*, "Good Copy, Bad Medicine" PBS, February 17, 1984, VTNA; Jean Seligmann et al., "The AIDS Epidemic: the Search for a Cure," *Newsweek*, April 18, 1983.

¹⁴³ Shilts, *And the Band Played On*, 301.

¹⁴⁴ In July of 1983, the *Gallup Poll*, reported that 77% of Americans heard about AIDS (the poll was conducted between June 6-13). Also, in the "note" section of the *Gallup Poll* results, the polling analysis indicated that the 77% statistic was interesting because few Americans heard of the disease months earlier. The *Gallup Poll* also quoted HHS Secretary Margaret Heckler speaking at a U.S. Conference of Mayors. She remarked at the conference that Americans should not worry about contracting the disease through "normal daily social contact." See: Dr. George H. Gallup, Founder and Chairman, *The Gallup Poll: Public Opinion 1983* (Wilmington: Scholarly Resources, Inc., 1983), 124-126; quote derived from 126

outlets when covering infectious disease phenomena. In fact, in 1984, the PBS media analysis show, *Inside Story*, provided critical insight into how some AIDS-related stories had sensational headlines or focused too heavily on the gay lifestyle.¹⁴⁵ Besides cogently describing the potential ramifications of Oleske's article, Shilts also discussed how scientific mistakes led to sensational news stories about the disease.¹⁴⁶

The controversy surrounding Oleske's conclusions in his *JAMA* article remained a sensitive issue for him years later. In an oral history, recorded in the mid-1990s, Oleske, referencing Shilts's book, said that he felt the author cast him as "sort of a second-rate New Jersey physician who was spouting fear about casual spread of the disease, which was not true."¹⁴⁷ Further compounding the controversy is a quote from Oleske that appeared in the *Star-Ledger* newspaper in January 1983, four months before the publication of the case report. The news story discussed his findings and how Oleske was one of the first to discover AIDS in children. At a meeting at St. Michael's Hospital in Newark, Oleske was quoted as saying that AIDS might be transmitted through "loving contact — hugging and kissing," which Oleske said is normal among families.¹⁴⁸ That same year he told *Heathstate*, the UMDNJ magazine, that the "appearance of AIDS in children strongly suggests...the work of an infectious agent capable of being transmitted through close contact in a household setting."¹⁴⁹

¹⁴⁵ "Good Copy, Bad Medicine,"

¹⁴⁶ Shilts, *And the Band Played On*, 299–300.

¹⁴⁷ Oleske oral history, Rutgers University, 6.

¹⁴⁸ Joan Whitlow, "Aiding the Fight Against AIDS: Doctor Call for Increased Federal Funding to Study Puzzling New Immune System Disorder," *Star-Ledger*, January 27, 1983.

¹⁴⁹ "AIDS Disease Seen in New Jersey Children," *Heathstate*, Winter 1983, page 27, Rutgers University Special Collections in the History of Medicine.

While Shilts and others were critical of Oleske's statements about casual contact, others were also critical of Shilts's depiction of scientists in his book. Writing a review of *And the Band Played On* for *Scientific American* in 1988, William A Blattner criticized Shilts's dichotomous characterization of some scientists as "hero[es] or villain[s], good or bad, fair-minded or homophobic." Of note, Blattner suggested that Shilts's thin analysis missed an opportunity to show how scientists were "real people, complex and multidimensional," with their own "faults and foibles."¹⁵⁰ Shilts certainly structured his assessment of Oleske and Rubinstein in such binary terms. Rubinstein was cast as the "better" scientist. Oleske was thus correct to think that Shilts portrayed him as a "second-rate" physician.¹⁵¹

Though Bazell wrote a scathing critique of Oleske's scientific findings, it was Shilts's account that stuck with Oleske, and for good reason. *And the Band Played On* is one of the most significant popular accounts about the emergence of, and early responses to, the epidemic. The book has had a lingering impact on the historical memory about AIDS in the U.S., and it remains an important chronicle of the first several years of the epidemic.¹⁵² The book's outsized role in the cultural history of HIV-AIDS in the U.S. also represents an important reminder about how we should remain critical of how Shilts portrayed the actors in his narrative. Rubinstein's scientific findings avoided making the problematic suggestions that could have engendered or reinforced fears among the

¹⁵⁰ William A Blattner, "Review of *And The Band Played On*, Shilts Randy," *Scientific American* 259, no. 4 (1988): 150.

¹⁵¹ This analysis about Shilts's narrative structure is informed by the following: Priscilla Wald, *Contagious: Cultures, Carriers, and the Outbreak Narrative* (Durham: Duke University Press, 2008), 213-263; McKay, *Patient Zero and the Making of the AIDS Epidemic*. These are not direct quotes from the *Contagious* and *Patient Zero*.

¹⁵² See, for example: Wald, *Contagious* and McKay, *Patient Zero and the Making of the AIDS Epidemic*.

American public that the disease was somehow “casually” transmitted. Oleske, on the other hand, mistakenly suggested that casual contact was a potential mode of transmission in his case report. But when placed within Shilts’s narrow narrative binary, there was little room for a nuanced discussion about how and why Oleske came to some of his conclusions. Instead, Rubinstein became the hero and Oleske the villain.¹⁵³

In the end, Shilts’s portrayal of Oleske did not damage the physician’s overall professional reputation, nor did Oleske’s comments about casual contact. Over the next several years, Oleske’s public and professional profile increased as he became one of the earliest and most vocal pediatric-AIDS advocates in the U.S. In the years immediately following the publication of his case report, Oleske most notably became part of a growing cohort of nurses, physicians, social workers, and public-health professionals who were trying to understand how best to respond to this new disease affecting adults and children alike.

Early Healthcare and Public Health Responses to Pediatric AIDS

As Oleske and Rubinstein were working on and subsequently published their case reports about pediatric AIDS, an epidemiologist from New York City’s Department of Health (NYCDOH) was already trying to get a handle on the scope of AIDS in children. Dr. Pauline Thomas was one of the early epidemiologists in New York City who gathered information about HIV-AIDS through a mixture of “shoe-leather” epidemiology and collaborative initiatives with physicians in the city. She surveyed everyone she could, from local hospitals to private practices, to record information about whether some

¹⁵³ Shilts, *And the Band Played On* 299 – 301.

patients were showing signs of the new disease. Along with Stephen Friedman, who was the Assistant Commissioner of Preventable Diseases, the pair interviewed patients, reviewed death certificates, and received help from venereal-disease-clinic workers who interviewed patients and collected sexual histories¹⁵⁴

When it came to pediatric AIDS, Thomas and the NYCDOH were particularly proactive in establishing and coordinating a system for understanding the biological and epidemiological profile of the disease in children. In late 1982, Thomas helped identify cases of AIDS among heterosexual women. Around the same time, Thomas and the NYDOH were developing case definitions for pediatric AIDS and establishing surveillance mechanism to capture suspected cases of the disease in children, all of which was coordinated with the CDC.¹⁵⁵

Once Oleske and Rubinstein began reporting cases of pediatric AIDS, Thomas and Friedman reached out to Oleske to be part of an informal task force on pediatric AIDS that was centered in New York City. Thomas and Friedman had begun pulling physicians and public health professionals into their orbit as early as 1982, and by the winter of 1983, the new task force was holding meetings. From 1983 to at least early 1984, the group met semi-regularly to discuss pediatric-AIDS surveillance in and around New York City and the U.S. They reviewed national and local guidelines for identifying

¹⁵⁴ James Keith Colgrove, *Epidemic City: The Politics of Public Health in New York* (New York: Russell Sage Foundation, 2011), 109. Information is also derived from: Dr. Pauline Thomas, interview by Jason M. Chernesky, February 7, 2018.

¹⁵⁵ Letter from Mary E. Chamberland to Harold Jaffee, December 6, 1982; Letter from David Sencer regarding the tenth DOH meeting about AIDS, December 8, 1982, and Minutes of AIDS meeting about AIDS, November 24, 1982; New York City Department of Health Draft of Workplan for AIDS Surveillance, Box 22, Folder "AIDS II Nov/Dec, 1982," New York Department of Health Commissioner Files, New York City Municipal Archives, New York, NY (hereafter cited; NYC DOH Commissioner Files).

whether a child had AIDS. They helped inform local child-aid organizations about the latest scientific knowledge regarding pediatric AIDS. They provided information to local healthcare professionals about the disease. And they tried to establish standard treatment approaches. Before the virus was identified and a blood test developed, the informal task force was an important collaborative effort that provided much-needed information about the developing epidemiology of pediatric AIDS, how some healthcare professionals were treating the disease, and the types of symptoms associated with the disease.¹⁵⁶

The formation and work of the informal task force also illustrated how competent and dedicated public health professionals, in a functioning city public health department, helped colleagues across the Hudson River who were dealing with an absence of local public health leadership. From the early 1970s through the mid-1980s, Newark had a city department of public health, but they were not well-organized or proactive in responding to HIV-AIDS. Commenting on the Newark health department's response to the disease, federal officials pointed out how the "city of Newark administration has...virtually ignored the AIDS problem and the City Health Department has denied that there is a unique problem in Newark." Those early interstate collaborations, and the coalescing of expertise that it produced, were thus an essential part in the growing scientific and public health knowledge about this new disease in children.¹⁵⁷

¹⁵⁶ Information about the informal task force is derived from a small collection of documents the Dr. Pauline Thomas provide the Special Collections at the Rutgers Medical Library in Newark. The collection includes meeting minutes from the group, some correspondence with guideline recommendations, and some statistical information (hereafter cited Thomas Personal Papers).

¹⁵⁷ An evaluation of Newark's Department of Health and the overall health of the city's residents and its health care institutions was the focus of a 1972 study: a report by the Center for Analysis of Public Issues, *The Doctor is Out... A Report on the Newark, New Jersey Division of Health, 1972*. The report provides a rather negative take of the health care and public health institutions in the city. See: The Center for Analysis of Public Issues, *The Doctor is Out... A Report on the Newark, New Jersey Division of Health*

Between 1983 and 1985, the science of pediatric AIDS also continued to evolve, particularly regarding the transmission of the disease between mothers and their children. In Miami, Scott conducted a set of important studies about the natural history of AIDS transmission in newborn children. She identified the first cases of AIDS in Haitian children whose mothers were not known IV drug users, and in 1985 she confirmed Rubinstein's hypothesis that the disease was vertically transmitted from mother to child. Though the exact biological mechanisms that resulted in vertical transmission of HIV-AIDS were still unknown, Scott drew on scientific precedent to argue that children acquired the disease perinatally. Scott thus presented further scientific evidence revealing that children, who did not receive tainted blood or blood products, contracted the disease from their mothers, "rather than from other household members."¹⁵⁸

(Princeton: The Center for Analysis of Public Issues, 1972), Rutgers Special Collections in the History of Medicine. The city's public health officials were also relatively absent when addressing the problem of AIDS in the 1980s. Consider, for example, an internal annual report published in 1986. In the report AIDS is only mentioned once in the context of the Sexually Transmitted Disease Clinics operations for that year: they held two workshops on AIDS. See: "Newark Department of Health and Human Services: 1986 Annual Report," Box 0391, Annual Reports, 1986, City of Newark Records Management Center, Newark, New Jersey; Quote derived from Stephen Margolis, Lela Baughman, J. William Flynt, Martin Kotler, *AIDS Children and Child Welfare*, (Washington, DC: U.S. Health and Human Services, 1988), 73. Since Newark lacked a robust public health agency, New Jersey's Department of Health was the central hub in the response to HIV-AIDS. In 1984, New Jersey's Health Commissioner, J. Richard Goldstein, established an Advisory Committee on the Acquired Immune Deficiency Syndrome. Unsurprisingly, Newark-area health care professionals were overrepresented on the committee. In addition, given the concentration of AIDS in the Newark area, there is some evidence that physicians in that city collaborated with one another to press New Jersey lawmakers and the governor to provided badly needed resources and funds. Information about the Advisory Committee is derived from the "Red Book" Report, Dr. Oleske Personal Papers. Information about health care workers pressing the state for funds is derived from, a folder of letters sent to New Jersey Governor Thomas H. Kean between 1983 and 1984: see, Box 3, Folder "AIDS," Governor Thomas H. Kean Records, Office of the Counsel, Jean M. Bogles, Records, 1982-1984, New Jersey State Archives

¹⁵⁸ Gwendolyn B. Scott et al, "Acquired Immunodeficiency Syndrome in Infants," *New England Journal of Medicine* Jan 12, 1984; [no Author] International Medical News "AIDS Diagnosed in 14 Miami infants From November 1980 to 1983; G. B. Scott et al., "Mothers of Infants with the Acquired Immunodeficiency Syndrome. Evidence for Both Symptomatic and Asymptomatic Carriers," *JAMA* 253, no. 3 (January 18, 1985): 363-66, quote derived from 365; Pizzo and Wilfert, *Pediatric AIDS*.

Between 1984 and 1985, the first guidelines for diagnosing AIDS in children were also published. For adults, AIDS was often determined by a set of criteria that included known risk factors, the presence of particular disease (e.g. Kaposi's sarcoma or PCP), and the age of the patient. For children, similar criteria were used, such as known risk factors (e.g. mother or father was an IV drug users) or disease associated with immune deficiency (e.g. interstitial pneumonitis or reparatory illness due to an opportunistic infection). However, diagnosing AIDS in children was difficult because they could be born with a congenital immune deficiency syndrome, so healthcare professionals had to determine if the immune deficiency was AIDS or some other illness. Also, unlike adults, the child's failure to thrive (FTT) — whether they were meeting their growth benchmarks, and FTT often indicated children had many conditions contributing to that poor health outcome — was another important sign the child had AIDS.¹⁵⁹ Adding to and aiding the diagnosis of AIDS was the FDA approval of the first blood test for HIV, the enzyme-linked immunoassay test (ELISA), in 1984. But even with the advance of the blood test, diagnosing children with HIV-AIDS remained complicated for years to come, largely because not all of the children seroconvert at birth.¹⁶⁰

While healthcare providers undoubtedly found diagnosing AIDS difficult in those early years, caring for children with the disease was a challenge as well. Between 1981

¹⁵⁹ CDC “Current Trends Update: Acquired Immunodeficiency Syndrome (AIDS) – United States *MMWR* 32 no 52 (January 6, 1984); Vijay Joshi, et al., "Pathology of suspected acquired immune deficiency syndrome in children: a study of eight children" *Pediatric Pathology* 2, no 1 (1984): 71-87; Arthur Ammann, "The acquired immunodeficiency syndrome in infants and children," *Annals of Internal Medicine* 103, no 5 (1985): 734-737.

¹⁶⁰ Information about ELISA derived from: Ammann, *Lethal Decisions*; Mirko D. Grmek, *History of AIDS: Emergence and Origin of a Modern Pandemic* (Princeton: Princeton University Press, 1993); Martha F. Rogers, et al "Advances and Problems in the Diagnosis of HIV Infection in Infants" in Pizzo and Wilfert, *Pediatric AIDS*, 1991.

and 1984, many of the healthcare professionals caring for children with HIV-AIDS had to improvise and adjust to the changing nature of this new disease. Facing a nursery full of children with AIDS, the social worker Ana Garcia, working at Jackson Memorial Hospital with Dr. Scott, remembered: "Everything was happening at one time and everything was by the seat of our pants. We didn't know what the hell we were doing. We were just intuitive."¹⁶¹

Between 1981 and 1985, the pediatric-AIDS programs in Newark, New York, and Miami transformed from informal organizations of a few health professionals to formal programs treating AIDS in children. Scott, with the help of a few physicians, a social worker and nurses were responsible for two hospital nurseries of children with AIDS. In the Bronx, Rubinstein, along with Dr. Novick and the social worker Anita Septimius established a pediatric daycare, with the help of a grant from the city, and a clinical care program.¹⁶² And in Newark, Boland and Oleske formed the Children's Hospital AIDS Program (CHAP).

CHAP was emblematic of the types of pediatric care facilities that emerged in the first four years of the epidemic and beyond. But unlike other facilities, the program's official name, and their first largesse, was linked to a New Jersey prison. According to Oleske, a prisoner called a local radio station, Z100, in 1985 asking to donate money to Children's Hospital in Newark — one of the prisoner's children had AIDS. A prisoner's association, the Lifers' Association at Rahway State Prison, was able to raise a thousand

¹⁶¹ Ana Garcia, interview, Jason M. Chernesky, August 3, 2018 (hereafter cited; Garcia interview).

¹⁶² Jeffrey M. Seibert and Roberta Ann Olson, eds., *Children, Adolescents & AIDS* (Lincoln: University of Nebraska Press, 1989); Garcia interview; Randy Shilts, "AIDS Overwhelms N.Y. Health System," *The San Francisco Chronicle*, February 14, 1985.

dollars for Children's Hospital. The Prisoner's association needed to make the check payable to an organization, but Boland and Oleske did not have one. "So Mary and I looked at each other," Oleske recalled, "and in the hallway decided that maybe they should make the check out to the Children's Hospital AIDS Program, CHAP...[i]t was probably not the greatest name because it had AIDS in it, but, you know...it worked."¹⁶³

At CHAP, as well as other facilities, a multi-team approach was used to care for children with the disease. Oleske and his colleagues explained this approach during a presentation in the mid-1980s. They considered pediatric AIDS, as many other healthcare professionals did, "a multisystem, chronic illness, which requires medical, nursing, social services, nutritional and neurological development support services."¹⁶⁴ That was the standard approach most of the healthcare teams took in New York City and Miami as well.¹⁶⁵ In fact, by the mid-1980s, the model of pediatric-AIDS care that was being established was built on the preexisting models of chronic-disease management used to treat illness in children such as cancer or cystic fibrosis.¹⁶⁶

The facilities also provided the periodic treatments of intravenous gammaglobulin (IVGG) therapy. Derived from human plasma, gammaglobulin was used in the prevention and treatment of infectious disease such as measles, mumps, and even polio around the middle of twentieth century. By the 1950s, it was used as a replacement

¹⁶³ Oleske oral history, Rutgers University.

¹⁶⁴ Presentation or unpublished article "Lessons from The Newark, New Jersey Pediatric AIDS Experience" James Oleske Dr. Connor and Nurse Boland's names are crossed out Sometime after 1987, Oleske Personal Papers.

¹⁶⁵ Information derived from: Seibert and Olson, *Children, Adolescents & AIDS* and Gary R. Anderson and Child Welfare League of America, eds., *Courage to Care: Responding to the Crisis of Children with AIDS* (Washington, DC: Child Welfare League of America, 1990).

¹⁶⁶ See Boland oral history. Also, I want to thank Cindy Connolly for providing her insight about how standards of care of chronic illnesses in children was well established before the emergence of pediatric AIDS.

therapy for immune deficiency illnesses.¹⁶⁷ Rubinstein and Oleske, having – trained in immunology, used IVGG for their patients early in the epidemic.¹⁶⁸ Children diagnosed with AIDS would make clinic visits about every three weeks to receive their IVGG therapies. IVGG was used to prevent recurring infections in children by boosting the immune system that was depleted by HIV. According to Nurse Judith Bonyai, who worked at CHAP in Newark, Oleske “swore by” the use of IVGG in boosting the child’s immune system.¹⁶⁹ Others were skeptical of IVGG’s effectiveness; Scott, for instance, did not provide her patients with IVGG. “I was a ‘do not give gamma globulin’ person,” she claimed. She recalled how Rubinstein and Oleske were “convinced that giving gamma globulin was very good to do...[a]nd I was not so convinced, but I was an infectious disease specialist and they were immunologists.”¹⁷⁰

Regardless of whether some physicians swore by IVGG or not, such treatments were part of broader models of care established during those early years of the epidemic. Given that the disease was incurable, nurses thus played a particularly important role because they were well-prepared for the frustrating work of caring for patients that would, for the most part, succumb to the disease. According to Boland, it was “harder for physicians than for nurses because our models are so different.” She stated that “a

¹⁶⁷ Melvin Berger, “A History of Immune Globulin Therapy, from the Harvard Crash Program to Monoclonal Antibodies,” *Current Allergy and Asthma Reports* 2, no. 5 (September 2002): 368–78.

¹⁶⁸ For uses of IVGG, see for example: Kevin M Shannon and Arthur Ammann, “Acquired Immune Deficiency Syndrome in Childhood,” *The Journal of Pediatrics*, Vol 106 No 2, February 1985; Theresa A. Calvelli and Arye Rubenstein, “Intravenous Gamma-Globulin in Infant Acquired Immunodeficiency Syndrome,” *The Pediatric Infectious Diseases*, 5, no. 3 (1986): S211 ; Asha Gupta et al, “Restoration of Suppressor T-Cell Functions in Children with AIDS Following IVGG Treatment,” *American Journal of Diseases of Children*, 140 no. 2 (February 1986): 143-146.

¹⁶⁹ Nurse Judith Bonyai oral history, interview by Jason M. Chernesky, August 28, 2017; There is also evidence that IVGG was being used in Newark as early as 1982. See: Letter to “ Dr. Franklin Behrle, Director of Pharmacy, United Hospitals from Dr. James Oleske, August 11, 1982, Thomas Personal Papers.

¹⁷⁰ Scott oral history; quote derived from 56.

physician...might say, ‘what’s the problem? I’m going to treat it. Here’s the disease; I’m going to fix it...nurses, philosophically, are...about the individual...the care vs. the cure.’¹⁷¹

But besides the labor of care, nurses were also responsible for the creation of the clinical and managerial infrastructures that led to and sustained those early models of pediatric-AIDS health care. Nurse Bonyai, one of the few nurses hired specifically to work at the newly formed CHAP center in Newark, was initially hired as part of research project that processed and sent lab specimens to the CDC. In addition to working on clinical research projects, nurses developed protocols, administered IVGG treatments, recorded side effects to treatments, educated families about the disease, managed routine patient check-ups, and organized clinical meetings between patients and healthcare workers.¹⁷² Although the training and culture of nursing made them better positioned to care for and respond to an incurable disease, this does not suggest that professional or institutional hierarchies were reversed in the age of AIDS. The work of pediatric nurses, instead, further reveals the central role nurses played in managing and developing clinical responses to a challenging new disease.¹⁷³

Old Trope, New Disease: the “Innocent Victims” of AIDS

As nurses and physicians began to better manage and understand pediatric AIDS, they were simultaneously dealing with a similar problem many other Americans coping

¹⁷¹ Boland oral history

¹⁷² Bonyai oral history

¹⁷³ This analysis is informed by, McGarrah, *Transcending AIDS*. On the culture of caring, as it related to AIDS, see: “Renee C. Fox, Linda H. Aiken, and Carla M. Messikomer, “The Culture of Caring: AIDS and the Nursing Profession,” *The Milbank Quarterly*, Vol. 69, Supplement 2 (Part 2), 1990: 226-256.

with AIDS faced: a dearth of resources for addressing the disease. Like gay-male activists, healthcare workers used every opportunity they had to raise awareness about pediatric AIDS with the hopes that such public knowledge would facilitate an increase in state and federal resources. For pediatric-AIDS healthcare workers, the news media became an effective tool for early efforts at awareness-raising. Those efforts were aided by an “innocent victim” narrative that had structured the way Americans came to understand sick, dying, and suffering children since at least the late nineteenth century.¹⁷⁴ Journalists and healthcare workers alike used such language (explicitly and implicitly) to draw attention to pediatric AIDS before and after 1985. However, as we will see in chapter three, the politics of AIDS would force many people to rethink their use of innocent-victim language when publicly discussing children with HIV-AIDS.

From 1983 to 1985, the AIDS epidemic garnered marginal news coverage in the U.S., which included AIDS among children and their families. Yet we see in that slim news coverage the almost reflexive use of the innocent-victim language. A *New York Times* article in early 1983 wrote that newly reported case of children with AIDS were “innocent bystanders caught in the path of a new disease.”¹⁷⁵ In April of 1983, *Newsweek*, one of the country’s popular news magazines, ran a cover story about the epidemic. The article did not provide many details about pediatric AIDS, but it did provide some of the few early, and moving, images of a Black mother holding her child, both of whom were

¹⁷⁴ This is informed by: Zelizer, *Pricing the Priceless Child*.

¹⁷⁵ Robin Marantz, “AIDS: A New Disease’s Deadly Odyssey,” *New York Times*, February 6, 1983; Other major newspapers reported on early cases of pediatric AIDS and quoted Oleske: See, for example: Jerry E. Bishop, “Widening Scourge: Lethal new Ailment Claims Another group of Victims,” *The Wall Street Journal*, December 10, 1982; Donald C. Drake, “A Mystery in the Blood,” *Philadelphia Inquirer*, January 2, 1983. Drake was also featured in the PBS *Inside Story* edition “Good Copy, Bad Medicine.” He spoke out against sensationalizing stories, like the emergence of pediatric AIDS as it related to the issue of “casual contact.”

dying from AIDS. The caption described how Celeste (the mother) stayed with her child, Ahmad, every night in the Newark hospital where he was cared for, despite her own struggles with the disease. “I’m trying to keep going,” she told *Newsweek*, “but there’s something happening inside me.”¹⁷⁶

By the fall of 1984, a few stories about AIDS in children were found on nightly news broadcasts, and in at least one early documentary about the epidemic. In both cases, viewers confronted images of infants with AIDS as doctors treated them, discussed their health problems, and mentioned the grim prognosis the children faced. In October of 1984, NBC *Nightly News* aired a segment about children with AIDS, specifically focusing on whether a Connecticut school district was going to admit an AIDS-positive kindergartener. The child’s name was Danny (pseudonym), a five-year-old Black child who viewers saw singing his A-B-Cs to his physician.¹⁷⁷ That same year, a PBS documentary, *AIDS: A Profile of an Epidemic*, featured five stories of people coping with AIDS, mostly. Yet one of the stories was about six-year-old Amar Hamilton, the first person we meet in the film, Amar, lived in the Bronx, was cared for by his Black grandmother, and had a mother who was dying from AIDS. Drs. Arye Rubinstein and Brian Novick took care of the child in the hospital, and Novick explained in the documentary how Amar was made deaf from an opportunistic infection.¹⁷⁸ Though explicit language about the “innocent victims” or bystanders of AIDS were not used, the innocent-victimhood narrative was nonetheless implied as viewers were confronted with

¹⁷⁶ Seligmann, “The AIDS Epidemic.”

¹⁷⁷ NBC *Nightly News*, “AIDS Children,” October 4, 1984, VTNA.

¹⁷⁸ PBS *AIDS: A Profile of an Epidemic*, accessed April 1, 2017, https://www.youtube.com/watch?v=hHssec0L_0c. It is unclear whether the documentary was nationally or regionally aired on PBS. I found reference to the documentary in the following collection: Box 48, July – December 1984, Folder, “July,” NYC DOH Commissioner Files.

infant children suffering from a deadly disease, even if those children appeared “healthy.”

Oleske, on the other hand, was quite explicit in using the language of innocent victimhood to draw attention to pediatric AIDS and its attendant problems. On January 1, 1984, *The Chicago Tribune* ran a frontpage story about Oleske, which was one of the first biographical sketches about the doctor at the time. In talking about AIDS in children, he reminded the journalist that many of the mothers he saw were IV drug users, and “[i]t’s not surprising that ... this is what we’re seeing in Newark. The city has a lot of poverty, a lot of ignorance and very few jobs. People turn to drugs.” He also commented about his frustration that the disease lacked financial support from federal agencies. “The Centers for Disease Control and the National Institutes of Health,” he said, “are doing a great job, but they’re interested in causes, not care.” Most importantly, he was explicitly about how he portrayed children with the disease: everyone “involved with AIDS is [a] victim, and I don’t like to stigmatize people, but let’s face it, some people are more sympathetic than others. Clearly, the children are innocent victims.”¹⁷⁹

In large part, such explicit references to innocent victims of AIDS was used to garner support from the federal government, which, by 1985, still did not provide significant financial support for pediatric AIDS. That same year, Rubinstein told Shilts — then working at the *San Francisco Chronicle* — that he struggled for a year to just get funding for a daycare center that would help families cope with the disease (that money came from the state of New York). He went on to say that it wasn’t until January 1985,

¹⁷⁹ Dennis L. Breo, “‘The Cure Will Come from the Kids’: Children of AIDS, Children of Hope,” *Chicago Tribune*, January 1, 1984.

that he was able to secure a social worker to care for the eighty families and children with the disease in his clinic.¹⁸⁰ In October 1985, while providing testimony at a Congressional hearing, Oleske reminded elected officials that pediatric AIDS care was woefully underfunded. As he did in the *Chicago Tribune* article, he relied on stories about sick and dying child to underscore the urgency needed to address the growing problem of AIDS in children. Instead of outwardly calling them innocent victims, he began his testimony with a story about the death of one of his patients and his mother. “Amad died after three years of care,” he told the Congressional committee, “his mother died six months later.” Similar to the types of opprobrium gay-male activists used to speak truth to power during those years, Oleske relied on the sick, dying, and dead patients in his clinic to call upon the federal government to seriously address the epidemic. Amad, he told Congressional leaders, was one of forty-five patients his team was struggling to treat under tight fiscal restraints. “I’m impressed with the \$46 million [the federal government spent]...for extramural programs,” he said, but “that money never filtered down to the clinical care centers in Newark, NJ.”

Funding for pediatric AIDS remained an issue in 1985, but the epidemic itself was gaining greater visibility. In July 1985, Rock Hudson announced he had AIDS, and the country first learned of Ryan White’s exclusion from high school due to his AIDS status. In the months and years to follow, White’s “innocent victim” status would become an important component in the way Americans came to reimagine the AIDS epidemic, and would largely overshadow similar school-related controversy surrounding children of

¹⁸⁰ Randy Shilts, “AIDS Overwhelms N.Y. Health System.”

color with AIDS.¹⁸¹ That same year, *Life* published a cover story with the sensational title “Now No One is Safe from AIDS.” The story largely focused on how a hemophiliac and his family was affected by AIDS. In the same story, Oleske was featured holding a three-year-old white girl who received the virus from a blood transfusion.¹⁸²

While AIDS gained greater visibility by 1985, pediatric AIDS was still largely marginal in the growing public discourse about the epidemic. But given the fact that children born with the disease only comprised roughly 1 percent of total cases of AIDS by that point (and would rise roughly 2 percent in the years to follow), children with the disease were still generating headlines. In the fall of 1985, the *Washington Post* published a story titled “The Littlest Victims,” which not only discussed how children received the disease through blood transfusion, but how the vast majority acquired it from their mothers.¹⁸³ Of course, the growing visibility of Ryan White and gay men with the disease overshadowed stories of children born with the disease.

By 1985, the nascent cultural visibility of children born with AIDS was made possible by their innocent victimhood status and through the advocacy of healthcare professionals that began speaking public about the problem of pediatric AIDS. The fact that pediatric-healthcare professionals became spokespeople for their patients was not unique, nor was it unsurprising given the nature of the disease. Early stories about pediatric AIDS in mass media rarely discussed the lives of the children’s families or the

¹⁸¹ See David Kirp, *Learning by Heart* and Gilman, 245-313.

¹⁸² James Kinsella, *Covering the Plague : AIDS and the American Media* (New Brunswick: Rutgers University Press, 1989).

¹⁸³ Margaret Engel, “The Littlest Victims: Children with AIDS Face Grim Treatments to Delay the Inevitable,” *Washington Post*, September 4, 1985. CDC “Acquired Immunodeficiency Syndrome (AIDS) Weekly Surveillance Report, AIDS Activity,” December 30, 1985.

plight of the parents. The almost total invisibility of the parents is also, perhaps, unsurprising. On the one hand, early stories about pediatric AIDS, when viewed through the narrow lens of innocent victimhood, resulted in a rigid, bifurcated narrative that could not include nuanced perspectives about parents, who were presumed responsible for their child's health. On the other hand, the parents' race, class, and residency — most lived in poor, urban environments — also rendered other parts of their lives, beyond reference to drug use, outside the cultural purview of many Americans.

That also helps, in part, explain Oleske's rise as one of the most outspoken and recognized spokespeople for pediatric AIDS, at least until Elizabeth Glaser founded the Pediatric AIDS Foundation in 1991. His position as one of a few pediatric-AIDS healthcare professionals at the time undoubtedly made him a useful source for journalists; many of the journalists almost exclusively spoke to pediatricians treating pediatric-AIDS patients. However, his near omnipresence in mass media differed greatly from his peers. That was likely due to his fondness for talking to the press. Boland recalled that Oleske's busy schedule often made him late for meetings; "unless it was an interview with the press, and then somehow, he was always on time."¹⁸⁴ And, of course, he used those meetings to discuss everything from the lack of funding, to the lack of attention paid towards children born with HIV-AIDS. Most importantly, Oleske, along with many other adults that would speak on behalf of children with HIV-AIDS, possessed a particular kind of cultural capital that extended beyond his status as a medical expert. Pediatric AIDS

¹⁸⁴ Boland oral history. In telling this story, Boland articulated how the staff often joked with Oleske about his punctuality when meeting with the press – which was not always the case when meeting with staff.

professionals were well-positioned to speak on behalf of their patients, and the patients' families, because they were intimately close to the communities they served, but did not shoulder the stigma attached to AIDS *and* urban poverty.



Image 3: Dr. James Oleske with a Patient, [No Date]
Source: Dr James Oleske's Personal Papers

That phenomenon would continue well after 1985. As pediatric AIDS gained greater cultural and political visibility in the next several years, a number of other healthcare professionals would not only speak publicly about the problem of pediatric AIDS, but also to the socio-ecological issues — such as poverty, IV drug use, and lack of adequate health care — that led to and exacerbated HIV-AIDS in children of color. But it would be the politics of poverty during the late 1980s and early 1990s that ultimately pushed pediatric AIDS to the top of the public agenda. In that context, narratives about innocent victimhood would merge with preexisting narratives about poor, urban communities of color.

CHAPTER 3: A FOCUS ON THE FAMILY: URBAN POVERTY AND THE MAKING OF A “FAMILY DISEASE,” 1986—1992

In December 1987, Cynthia Givens was featured in a special news report about AIDS in New Jersey. In the *Star-Ledger* article "Kids with AIDS," the story described how Cynthia was born with the disease, her mother was an IV drug user, the child was orphaned at a hospital in Newark, and she was later cared for by her foster mother, Jean. By 1989, the now five-year-old Cynthia had become the poster child for the Urban League's Foster Care Program, which included a local public service announcement about the program that showed the child "romping in her Newark backyard, [and] playing with her cat." It was perhaps because of her short-lived and local celebrity that Cindy, unlike many other children with AIDS, was memorialized in the newspaper when she died in December of 1989.¹⁸⁵

Cynthia was not just a child representative for the Urban League's foster care program. Her momentary public profile is representative of an important moment in the history of pediatric AIDS in the United States. A few years after pediatric-AIDS advocates like Oleske began to speak publicly about the problem, HIV-AIDS in children gained a heightened degree of national attention. This chapter shows that between 1986 and 1992, children with AIDS garnered increased cultural and political visibility at a time when public awareness of the epidemic was growing, and as elected officials and policy makers began to take greater steps towards addressing the epidemic. Although the

¹⁸⁵ Judy Peet, "Kids with AIDS: Jersey struggles with a 'deadly legacy,'" *Star-Ledger*, December 20, 1987; Janice Phipps, "Girl; star of AIDS public service ads dies at 5," *Star-Ledger*, December 9, 1989; For information about the Urban League's foster care program, see New Jersey Council of Urban Leagues, "Pediatrics AIDS Foster Care Program," 1989, Box 1, Folder 11 NJ AIDS Collection; See also: "Foster Parent with AIDS Kids Program Launched on WWOR," *The Amsterdam News*, September 23, 1989.

numbers of children with the disease remained around or below 2 percent of all reported cases of HIV-AIDS, stories of orphaned "boarder babies" in hospitals and concerns about the possibility of growing numbers of children born with the disease helped draw more national attention to the problem of pediatric AIDS.¹⁸⁶ Children like Cynthia also came to represent the changing demographics of the epidemic: as new cases among gay men were leveling off, reports about the so-called "changing face of AIDS," began highlighting how more people of color were acquiring the disease.¹⁸⁷

But children were more than representatives of changing epidemiological trends associated with the epidemic; they also became ensnared in political conversations about the meaning and causes of urban poverty. As the nation paid greater attention to issues such as crack and crime in poor urban communities, pediatric AIDS became a biological pathology that was seen as inextricably linked to the "social pathologies" many Americans associated with socio-environmental conditions of "the inner city."¹⁸⁸ Long-standing popular perceptions of U.S. inner cities — especially those related to the "underclass" and families of color — loomed large in national conversations about pediatric AIDS. In that context, children with HIV-AIDS became both "innocent victims" of the epidemic *and* the inner city. National concerns and conversations about poor, urban communities of color helped push pediatric AIDS to the top of the public agenda.

¹⁸⁶ CDC "U.S. AIDS Cases Reported Through December 1992," *HIV/AIDS Surveillance, Year-End Edition*, Issued February 1993.

¹⁸⁷ Richard Stengel, "The Changing Face of AIDS," *Time*, August 17, 1987.

¹⁸⁸ The use of "the inner city," here, represents how Americans came to use the phrase to describe poor, urban communities of color who often live in urban environments suffering from disinvestment. In this respect, "inner city" displaced, but did not totally replace, "the ghetto" as a type of shorthand for describing such urban communities and places.

While narratives about the underclass and social pathologies structured many of the conversations about pediatric AIDS specifically — and AIDS in urban communities of color generally — some sought to highlight how the disease was affecting families. In that context, references to AIDS as a "family disease" became more present in public and political discussions about the disease in the late 1980s. AIDS was not, of course, the first time Americans framed an infectious illness as affecting the entire family. In this regard, syphilis was most analogous to HIV-AIDS, as it was framed by public health professionals as a family-unit disease in the early twentieth century as well. In this example, the geography of blame surrounding syphilis was quite similar to that of AIDS, especially when considering how anti-syphilis campaigners cast married women and their unborn children as "innocent victims" of taboo male sexual behavior, and other women — namely prostitutes or those deemed to be sexually promiscuous — as potential vectors of disease. But the concerns about white families affected by syphilis in the early twentieth century were different than late-twentieth century discussions about AIDS as a family disease.¹⁸⁹

Pronouncements about AIDS as a family-unit disease took on different meaning in the late 1980s and early 1990s. When considering how AIDS became a "family disease," we must understand how that particular framing of the disease collided with, and was shaped by, the politics of "family values," urban poverty, and the pathologization of poor urban families of color in the late twentieth century. In the end, the family-

¹⁸⁹ According to Allan M. Brandt: "[a]s venereal disease became a focus for Progressive fears concerning the future of the family in the first years of the twentieth century, physicians increasingly considered it their responsibility to protect the institution of marriage from the introduction of disease," see: Allan M. Brandt, *No Magic Bullet*, 17.

disease framing of AIDS was short-lived and relegated to the margins of the larger, evolving public discourse about the epidemic during these years. But the emergence of the family-disease narrative represents an important phenomenon when understanding how Americans came to understand pediatric AIDS in this era. The rise of the family-disease discourse reveals how the social and geographic imaginaries that structured the way Americans understood poor urban areas as a foreign territory within the borders of the nation ultimately made pediatric AIDS into just another problem of “the inner city.”

Urban “Pathologies,” Families, and the Rise of the Underclass

The story of pediatric AIDS in the late 1980s and early 1990s is tied to a pervasive and popular poverty discourse that emerged roughly two decades before the epidemic began. Beginning in the 1960s, Americans were introduced to a new concept that helped redefine urban poverty in the U.S. In his popular book *The Other America* (1963), Michael Harrington popularized the idea of the “culture of poverty,” which was originally developed by the anthropologist Oscar Lewis. Harrington’s book became a touchstone in a new focus on poverty in the U.S., in which he described poverty as, “a culture, and institution, a way of life...the family structure of the poor...is different from the rest of society.” Such differences also included how the poor possessed a particular language, psychology, and worldview. Harrington exclaimed that, to be impoverished “is to be an internal alien, to grow up in the culture of poverty that is radically different from the rest of society.”

When popular writers like Harrington articulated the purported presence and problems of the culture of poverty, he was speaking about both the urban and rural

poor.¹⁹⁰ That changed in the context of the Civil Rights movement and violent uprisings in U.S. cities during the mid-1960s. Politicians, policymakers, liberals, conservatives, and the public shifted their attention to plight of poor communities of color. This resulted in the urbanization and racialization of poverty discourse in the U.S. In 1965, the publicizing of, and eventual backlash towards, Daniel Patrick Moynihan's *The Negro Family: The Case for National Action* (1965), reflected and influenced how many Americans came to understand poor families of color. Though he never used the words "culture of poverty," many of the themes popularized by social scientists and writers of the era structured Moynihan's analysis of poverty among some Black communities. Central to his assessment of Black, urban poverty was how legacy of slavery and unemployment weakened the structure of the African American family. As a result, the Black family was caught in a "tangle of pathology," a phrase borrowed from the psychologist Kenneth B. Clark. The social pathologies that ensnared the Black family in an intergenerational "cycle of poverty" included things like crime, juvenile delinquency, alienation, substance abuse, and "absent" fathers. "At the center of the tangle of pathology," Moynihan wrote, "is the weakness of the family structure."¹⁹¹

¹⁹⁰ Oscar Lewis, *Five Families; Mexican Case Studies in the Culture of Poverty*. (New York: Basic Books, 1959); Oscar Lewis, *La Vida; a Puerto Rican Family in the Culture of Poverty--San Juan and New York*. (New York: Random House, 1966); Michael Harrington, *The Other America: Poverty in the United States*. (Baltimore: Penguin Books, 1963); Harrington's quotes are derived from pages 15-17. The history of how the culture of poverty discourse and ideas developed -- and eventually mainstream -- is derived from, Katz, *The Undeserving Poor* ; 9-23.

¹⁹¹ Lee Rainwater, *The Moynihan Report and the Politics of Controversy; a Trans-Action Social Science and Public Policy Report* (Cambridge, Mass: M. I. T. Press, 1967), 39-125; The historical perspective, here, is derived from Katz, *The Undeserving Poor*. For Clark's use of the "tangle of pathology" see, Kenneth Bancroft Clark, *Dark Ghetto : Dilemmas of Social Power*, 1st ed. (New York : Harper & Row, 1965.), 81-110.

Moynihan met stiff and warranted criticism for his portrayal of the Black families' relationship towards, and position in, what he called a "tangle of pathology." Although the report was similar to other interpretations about poverty among Black and other communities of color, Moynihan possessed a cultural blind spot when it came to how he portrayed the Black family as the epicenter for what he called the tangle of pathology. Just as the Civil Rights movement and violent civil unrest of the mid-1960s exposed the harsh realities of Black life, which engendered – engendering a new focus on urban poverty, it also marked a rise in a new Black empowerment ethos that drove many to actively critique certain portrayals of the Black community. Civil Rights leaders and others sympathetic to the movement saw Moynihan's interpretations as culturally insensitive by perpetuating a perception of the Black community as passive victims, rather than actively achieving significant progress over the decades. Journalists, often obscuring Moynihan's argument about how unemployment weakened Black communities, also focused on his interpretation of the Black family's association with pathological behavior. And critiques of the report, and that of other culture-of-poverty theorists, pointed to how such assessments obscured similar phenomena occurring among poor whites in the United States.¹⁹²

¹⁹² Rainwater, *The Moynihan Report and the Politics of Controversy*; The historical perspective, here, is derived from Katz, *The Undeserving Poor*. For Clark's use of the "tangle of pathology" see, Kenneth Bancroft Clark, *Dark Ghetto : Dilemmas of Social Power*, 1st ed. (New York : Harper & Row, 1965.).

¹⁹² The literature about, and critiques of, Moynihan's report is vast. My discussion of his leaked report in 1965 is not meant to unpack Moynihan's intentions, goals, or political motivations for writing the report. Nor is this meant to unpack deeper or different meaning that has not been covered by other scholars. Instead, Moynihan's report, and the controversy surrounding it, is meant to be a historical marker in the late-twentieth century discourse about poverty, as it related to black communities. In the wake of Moynihan's report – and the controversy surrounding it – the terms of the debate, and the narratives associated with, urban poverty shifted in the U.S. According to social scientists Douglas S. Massey and Robert J. Sampson, "For decades, the terms of the public debate were skewed away from structural issues such as segregation, discrimination, and economic restructuring and toward individual issues such as

The backlash to Moynihan's report helped transform subsequent social science research about the causes of entrenched poverty among communities of color a politically difficult venture. By the end of the 1970s and into the early 1980s, the culture-of-poverty script thus remained a powerful framing device by which popular stories about inner-city poverty became mainstream in the U.S. As the socioeconomic conditions worsened in some cities through the 1970s, a new terminology rose to the top of the public discourse about entrenched urban poverty: the "underclass." The popular image of the underclass was captured in a 1977 front-page article in *Time Magazine* titled, "The Minority within a Minority: The Underclass." The geography of the underclass was foreign to many Americans, the article suggested, "a different world, a place of pock-marked streets, gutted tenements and broken hopes." Those spaces housed and produced "a disproportionate number of the nation's juvenile delinquents, school dropouts, drug addicts and welfare mothers, and much of the adult crime, family disruption, urban decay, and demand for social expenditures."¹⁹³

By the early and mid 1980s, the underclass was a central component within intellectual and policy debates about inner-city poverty. Books such as Douglas G. Glasgow's *The Black Underclass* (1981), Ken Auletta's *Underclass* (1982), and Charles

values, culture, and morality." See: Douglas S. Massey Massey and Robert J. Sampson, "Introduction: Moynihan Redux: Legacies and Lessons," *The Annals of the American Academy of Political and Social Sciences*, 621, (2009): 6-27. For historical perceptive and critiques about the legacy of Moynihan's report, see: Katz, *The Undeserving Poor*, 102-202; Dorothy E. Roberts, *Killing the Black Body : Race, Reproduction, and the Meaning of Liberty*, 1st ed. (New York: Pantheon Books, 1997), 25; 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.); Michael B. Katz, *Why Don't American Cities Burn?*, 1st ed. (Philadelphia: University of Pennsylvania Press, 2011), 101-150; Mitchell Duneier, *Ghetto: The Invention of a Place, the History of an Idea*, 1st edition., (New York: Farrar, Straus and Giroux, 2016).¹⁹³ "The American Underclass: Destitute and desperate in the land of plenty," *Time*, August 29, 1977, 14-27.

Murray's *Losing Ground* (1984) were representative of and, in the case of Auletta and Murray, helped secure particular views about the causes of urban poverty and the persistent social pathologies associated with the underclass in American inner cities. While Glasgow attempted to highlight how structural forces helped produce and exacerbate more pernicious forms of urban poverty, Murray's focus on the cultural and social explanations as to why poverty persisted became popular within the conservative political climate of the early-to-mid 1980s. For Murray, welfare programs worked as a disincentive in communities of color that, in his arguments, led to an unwillingness to work or keeping together nuclear families. In Murray's arguments and analyses, the values and behaviors of the underclass were thus reinforced by welfare programs and policies. Notably, Murray claimed that the structure of the Black family, particularly single women with children, was a particularly salient explanation for persistent, entrenched forms of poverty in Black communities.¹⁹⁴

By the late 1980s, reactions to Murray's arguments produced significant, alternative explanations about the roots and persistence of urban poverty in the U.S. One of the most important and influential voices was the University of Chicago sociologist

¹⁹⁴ Douglas G. Glasgow, *The Black Underclass : Poverty, Unemployment, and Entrapment of Ghetto Youth*, 1st edition, (New York : Vintage Books, 1981); Ken Auletta, *The Underclass* , 1st ed. (New York : Random House, 1982.); Charles A. Murray, *Losing Ground--American Social Policy, 1950-1980* (New York : Basic Books, 1984.); The historical perspective and analysis about the above publications is derived from Katz, *The Undeserving Poor*, 203-267 and Katz, *Why Don't American Cities Burn?*. In this latter publication, Katz also suggests that Auletta's book "secured [the underclass's] dominance in the vocabulary of inner-city pathology," 102. Regarding the reception of Murray's arguments and analysis Christopher Jencks and Paul E. Peterson, wrote that "Murray's explanation resonated well with the political climate of the early 1980s. Americans were suspicious of big government, the welfare state, and the political demands made by minority spokespersons." See: Christopher Jencks and Paul E. Peterson, eds., *The Urban Underclass* (Washington, D.C: Brookings Institution, 1991), 14. For additional haptoral perspective on the underclass, see, for example: Michael B. Katz ed., *The "Underclass" Debate: Views from History* (Princeton, N.J: Princeton University Press, 1993) Julilly Kohler-Hausmann, *Getting Tough: Welfare and Imprisonment in 1970s America* (Princeton: Princeton University Press, 2017), 289-298.

William Julius Wilson. In a companion piece to an article about the Black underclass in the spring of 1986, *U.S. News and World Report* published a dialogue between Wilson and Murray that reflected the divergent intellectual views surrounding urban poverty. In his response to Murray, Wilson argued that the reasons for Black-male joblessness was largely the result of low-skill jobs leaving central cities and because of race-based hiring practices, which often excluded Black men.¹⁹⁵ A year later, Wilson's book *The Truly Disadvantaged* (1987) further detailed how and why poverty remained a significant problem in many urban communities of color. The book also provided liberals in the U.S. a potent academic study by which to counter conservative arguments that sought to dismantle welfare programs. And considering the use of the term "underclass," Wilson deployed such language to highlight how communities of color had been left behind during the shifting economic and social landscapes of the 1960s and 1970s.¹⁹⁶

Regardless of whether one believed that urban poverty was the result of structural inequalities or cultural causes, the inner city nonetheless remained, for many Americans, a foreign landscape that seemed to be increasingly under siege. By 1986, little changed in the public discourse about depictions of U.S. inner cities. Similar to the *Time Magazine* article of 1977, a 1986 article in *U.S. News and World Report* titled "A Nation Apart" featured the problems communities of color faced in poor neighborhoods, accompanied

¹⁹⁵ William Julius Wilson and Charles Murray, "Dialogue: Debating Plight of the Urban Poor," *U.S. News and World Report*, March 3, 1986, 21.

¹⁹⁶ William J. Wilson, *The Truly Disadvantaged: The Inner City, the Underclass, and Public Policy* (Chicago: University of Chicago Press, 1987); See also, Katz, *Why Don't American Cities Burn?*

by images of single-mothers, dilapidated apartments, trash-riddled lots, and the homeless warming themselves with by fires.¹⁹⁷

Such depictions of the inner city also accompanied stories about poor, single-mother households, even among those sympathetic to the problems Black families faced in American cities. Using Newark, New Jersey as his case study, Bill Moyers's award winning CBS news special, *The Vanishing Family — Crisis in Black America*, (1986) echoed the familiar story about disruption of the Black family as it related to inner city problems and poverty. Like other popular press accounts, the inner city itself — its population, geography, and dilapidated built environment — was also an important character in such stories. Introducing viewers to the news special, Moyers, standing in front of a vacant lot and abandoned, depilated building, introduced viewers to his news special, stating: “this is Newark, New Jersey, one of America’s inner cities — inner city is a polite word for ghetto.” By that point, stories about the underclass and the inner city could be found in other mass media accounts as well.¹⁹⁸

Adding to the reported problems of intergenerational poverty was the emergence of, and deleterious effects related to, crack-cocaine. In 1986, mass-media attention towards crack-cocaine accelerated. The heightened level of attention was captured, for example, in a *Newsweek* cover and set of stories about the problem of crack-cocaine in

¹⁹⁷ David Whitman et al, “A Nation Apart,” *U.S. News and World Report*, March 17, 1986, 18-21. See also, Katz, *The Undeserving Poor*, 185-235.

¹⁹⁸ Bill Moyers, “The Vanishing Black Family: Crisis in Black America,” *CBS News Special Report*, accessed January 1, 2016, <https://www.youtube.com/watch?v=vrw416MnJ8>. For the report’s Peabody Award, see “CBS Reports: The Vanishing Family – Crisis in Black America,” Peabody: Stories that Matter, accessed, January 1, 2017, <http://www.peabodyawards.com/award-profile/cbs-reports-the-vanishing-family-crisis-in-black-america>Cite. The report was also praised in the major news outlets, such as *The New York Times*; see John Corry’s review, “TV: ‘CBS Reports’ Examines Black Families,” *The New York Times*, January 25, 1986.

the U.S.: “The Drug Crisis: Crack and Crime.” Writing about the drug’s impact on American cities, the article stated how the “crack war” was “turning the ghettos of major cities into something like a domestic Vietnam.”¹⁹⁹ Depending on who one asked, the growing national focus on crack-cocaine reinforced, or was symptomatic of, prevailing cultural perceptions of the “pathologies” of the inner city. Given the political divides that structured the poverty discourse during the late 1980s, the problems of the inner city were perceived by many Americans as either the result of taboo behaviors or structural inequities. Most importantly, the problem of crack-cocaine further drew the attention of policymakers and the public towards the multiple problems of the inner city, and the use of illicit drugs among women who were or might become pregnant.²⁰⁰

Boarder Babies and the Inner City

Pediatric AIDS began to gain more national attention within that context. In February of 1986, *NBC Nightly News* featured a story about children born to women who used illicit drugs. The piece, titled "Drug Babies," explained that children born to women who used drugs like cocaine or heroin was becoming a problem in the United States among poor and affluent women alike.²⁰¹ During the spring of that year, a Congressional subcommittee held a hearing titled *Placing Infants at Risk: Parental Addiction and*

¹⁹⁹ Tom Morganthau, “Crack and Crime,” *Newsweek*, June 16, 1986, 16-22. In their edited volume about crack in America, the sociologists Graig Reinerman and Harry G. Levine show that the speed and volume of media coverage about crack-cocaine grew and peaked between 1986 and 1992. Also, they state that, “Crack attracted the attention of politicians and the media because of its downward mobility to and increased visibility in ghettos and barrios.” See: Craig Reinerman and Harry G. Levine, “Crack in Context: America’s Latest Demon Drug,” quote derived from 19; and Craig Reinerman and Harry G. Levine, “The Crack Attack,” in Craig Reinerman and Harry G. Levine eds. *Crack in America: Demon Drugs and Social Justice* (Berkeley: University of California Press, 1997).

²⁰⁰ Farber, *Crack*, 129–62.

²⁰¹ “Drug Babies,” *NBC Nightly News*, February 18, 1986, VTNA.

Disease. The reason for the hearing, Chairman George Miller (D-CA) stated, was because of "a new and extremely disturbing threat to the well-being of babies: The severe health calamities which befall infants whose mothers abuse drugs, alcohol, or tobacco, or who suffer from AIDS."²⁰² The inclusion of children born with the disease in the Congressional hearing represented how pediatric AIDS straddled two overlapping phenomena during the mid-1980s: growing concerns about pediatric AIDS and blaming mothers-to-be for their consumption choices, especially their use of drugs and alcohol.²⁰³

Given the close proximity between IV drug use and pediatric AIDS, it is unsurprising that early Congressional responses to the disease placed that health problem within the long tradition of scrutinizing and surveilling the behavior of pregnant women and women of childbearing age. Though reasons why some children were born with the disease were not simply due to a mother's use of drugs intravenously, Congressional leaders nevertheless tried to reduce the problem of pediatric AIDS to a problem of drug use. Though IV drug use was one vector for transmitting the disease to would-be mothers, it was not the only one. Citing statistics from the CDC, the committee showed that 75 percent of children with AIDS acquired the disease from "their mother either during pregnancy, or immediately after birth," and of those children 61 percent were born to women that were "drug users themselves." The referenced statistics also showed that 12 percent of women contracted the disease through sex with a male partner who used IV

²⁰² *Placing Infants at Risk Parental Addiction and Disease: Hearing before the Select Committee on Children, Youth, and Families, 99th Congress, May 21, 1986.* (1986) (statement of Congressman George Miller); quote derived from page 1.

²⁰³ This analysis is informed by Leslie J. Reagan's, *Dangerous Pregnancies: Mothers, Disabilities, and Abortion in Modern America* (University of California Press, 2010), specifically pages 225-231; and Janet Lynne Golden, *Message in a Bottle: The Making of Fetal Alcohol Syndrome* (Cambridge, Mass.: Harvard University Press, 2005).

drugs. The remainder of the cases were the result of blood transfusions.²⁰⁴ For the committee, the 61-percentile helped dictate the conversation about pediatric AIDS.

The omnipresence of IV drug use in the growing public discourse about the disease also made it difficult for pediatric AIDS advocates to get needed resources for coping with the disease itself. Oleske, who testified before the committee, acknowledged that drug use was an important issue. In New Jersey, Oleske stated, the majority of the children born with HIV-AIDS were born to “drug-using women,” but he also reminded the committee that “we ought to direct our efforts towards that [drug use], because there are a lot of children, and there are a lot of women, and a lot of mothers suffering the terrible cost of drugs.” Yet he also lamented that the very fact that pediatric AIDS was closely associated with IV drug use further perpetuated the lack of action needed to mitigate the problem. He stressed the need for more resources because, in his experience, there was little charitable support for women and children with HIV-AIDS. After all, he told the committee, “[w]e are not having movie stars giving benefits for children born to drug users.”²⁰⁵ Besides suggesting that children and mothers with AIDS did not receive needed resources to cope with illicit drug use *and* AIDS, his comment also underscored what he felt was an additional dilemma facing the women and children he saw in Newark: the country was not paying attention to them because they were poor, drug-using women of color who lived in specific urban environments.

This became a point of contention among Oleske and his fellow panelists at the hearing when Representative Dan Coates (R-IN) questioned how he was to justify setting

²⁰⁴ *Placing Infants at Risk*, 5.

²⁰⁵ *Placing Infants at Risk*, 21-23 (Statement of Dr. James Oleske); quotes derived from pages 21 and 22..

aside taxpayer funds to help children and their mothers cope with the disease. “We are talking about a disease,” Coates said, “at least in the public’s mind, [that] is sperate from [others] that affect the general public.” He added that “many people see this as something that...would not have happened in the first place, without individuals engaging in illegal or other acts that a lot of society feels are abnormal.” Benjamin Walker, Jr., who worked with drug users in New York City, interrogated the subtext of Coates’s remarks. He asked: “Are we repeating history where, in the 1960s, you used to say that drug addiction was a local problem, it was just a minority problem, or a poverty problem? Are we repeating history by saying that it is the same...with AIDS, and wait until it hits the middle class and the rest of the population before we deal with it?” Oleske provided a sobering rejoinder that illuminated the reality of pediatric AIDS in Newark. He reminded the committee that it was not “funny” caring for children, most of whom died. If you “worked every day up in Newark,” he exclaimed, “and saw what we saw, you would come down here...and get a little angry.” He ended, to applause, that: “[y]ou want people to listen. We want you to know about the problem. We would like you to do something about the problem. You guys write the checks. We just care for the patients.²⁰⁶”

Funding disparities and obstacles aside, pediatric AIDS also gained particular attention as orphaned children with the disease began to overwhelm some city hospitals. Between 1986 and 1987, the number of “boarder babies” — newborn children medically cleared to leave a hospital, but whose parents could not take care of them — was– were

²⁰⁶ *Placing Infants at Risk*, 86

growing in some U.S. cities. Major news outlets covered the story.²⁰⁷ Places like Miami, Newark, and New York City, all struggled with orphaned, HIV-AIDS-positive children. New York City was particularly inundated: at Harlem hospital, for example, roughly 20 percent of the sixty beds on the pediatric ward there was housing a boarder baby.

Children lived for weeks or months in the hospital; some newborns never left the wards, dying there before being transitioned out of the hospital. In one extreme cases, a child in Miami lived in the hospital for two and a half years. Many of the children orphaned in hospitals were there because their parent or parents had died from AIDS, were too sick to care for the children, or were prevented from caring for their child. Due to other circumstances²⁰⁸

Children were also living in hospitals because of issue related to transitioning them to a foster facility or foster home. In New York City, the increase in children waiting for foster care as a result of AIDS or a combination of factors overwhelmed the system.²⁰⁹ Undoubtedly, the medical conditions and the cost of care factored into the child's unwanted status. According to one news article, the New York City Human

²⁰⁷ The earliest use I found of "boarder baby," for children orphaned at hospitals, was in 1970. See: Jean Murphy, "Involvement Opportunities," *Los Angeles Times*, February 1, 1970. In 1976, references to boarder babies and drug-using mothers also appeared in the press. See: Ronald Sullivan, "New York State is asked to pay for moving city 'boarder babies,'" *The New York Times*, December 16, 1976. For boarder babies and HIV-AIDS, see, for example, "Who will care for the boarder babies," *The New York Times*, November 30, 1986; Kenneth E. Raske, "Letter: On Foster Care, 'Where the Boarder Babies come From,'" *The New York Times*, December 29, 1986; Bruce Lambert, "Boarder Babies Burden Hospitals," *The New York Times*, February 8, 1987.

²⁰⁸ Margolis et al, *AIDS Children and Child Welfare*, 6–10; 66–76. According to this report, pediatric AIDS health care professionals in Miami and Newark had less of a problem placing children in foster care or with extended families.

²⁰⁹ The Vera Institute for Justice published an extensive report about foster care and drug trials among children in New York City foster care. In their report, they provide extensive details about the problem of boarder babies and the strained foster care system. See: Timothy Ross and Anne Lifflander, *The Experiences of New York City Foster Children in HIV/AIDS Clinical Trials* (Vera Institute of Justice, January 2009).

Resources Administration also attributed the lack of foster care placement to “a lack of foster parents willing to take in children...who may be addicted to drugs or have AIDS themselves.”²¹⁰ Compounding the problem of boarder babies was the removal of newborn children from parents who used illegal drugs. For example, at Brooklyn’s Kings County Hospital some 130 children were orphaned “or removed from their parents. They must languish in hospitals cribs for an average of two months because the city hasn’t arranged for emergency foster care.”²¹¹

Though ultimately few in number, boarder babies with HIV-AIDS posed a financial burden on hospitals. Physicians at Harlem Hospital, which had some of the highest number boarder babies in the country, published a study in *JAMA* demonstrating the cost of caring for and housing children with HIV-AIDS. From 1981 to 1986, they estimated that the total cost was around \$3,368,597. The per-day cost of children sick with opportunistic infections was \$705, and those patients that were less sick, but homeless, cost \$466 per day.²¹² That was especially a problem for hospitals that were chronically under-resourced and staffed.²¹³

Meanwhile, the national attention towards boarder babies coincided with shifting conversations about HIV-AIDS and the inner city. Early in 1987, the *Chicago Tribune*

²¹⁰ Quote derived from: Bruce Lambert, “Boarder Babies Burden Hospitals”; Also see, Ross and Lifflander, *The Experience of New York City Foster Children*.

²¹¹ “Who will care for the Border Babies”; Dorothy Roberts also writes about the issues of foster children and race, as well as the removal of children from drug-using women that gave birth to children. See: Roberts, Dorothy E. *Killing the Black Body* and Roberts, Dorothy, *Shattered Bonds: The Color of Child Welfare* (New York: Basic Books, 2002).

²¹² James D. Hegarty et al., “The Medical Care Costs of Human Immunodeficiency Virus-Infected Children in Harlem,” *JAMA* 260, no. 13 (October 7, 1988): 1901–5; See also: Margolis, *AIDS Children and Child Welfare*

²¹³ See, for example: Stephen W. Nicholas and Elaine Abrams, “Boarder Babies with AIDS in Harlem: Lessons in Applied Public Health,” *JAMA*, 92, no. 2 (February 2002): 163-165.

ran an article titled, “Underclass falling victim to AIDS siege.” The article stated that AIDS was “no longer the disease of homosexual middleclass white men,” because it was increasing in “impoverished minority, men, women, and children, due largely to the spread of the disease among intravenous drug users and male and female prostitutes.” Speaking about such changes, the Director of the Illinois Department of Public Health was quoted as stating, “[a]s we see more...children who are believed to be innocent victims, the public will come to understand that AIDS is not purely a gay disease...all of us can be at risk.”²¹⁴ Calls about the broader risk of HIV that pediatric AIDS revealed did not seem to be a consistent public message until 1987.

By the summer of that year, the boarder baby problem had become the public representative of both pediatric AIDS and its attendant problems associated with poor urban communities of color. On NBC *Nightly News* a special segment titled “AIDS Babies” reported how orphaned children with HIV-AIDS were often the result of a mother that had used drugs intravenously or had had sex with IV drug users, especially among communities of color. In August 1987, a *Time* magazine article titled “The Changing Face of AIDS,” explained that “Doris White” (pseudonym), a young Black woman from Harlem, contracted HIV from her IV-drug-using husband. As the article mentioned, “[s]tories like Doris White’s are becoming common in inner-city ghettos: everyday someone else who got high is getting sick. So are their lovers, and so are their children.”²¹⁵ The rising visibility of pediatric AIDS and boarder babies coincided with

²¹⁴ Wes Smith, “Underclass falling victim to AIDS siege,;,” *Chicago Tribune*, February 16, 1987; Roland Kotulak, “AIDS underreported for Chicago Infants,” *Chicago Tribune*, February 8, 1987.

²¹⁵ “AIDS Babies” NBC, *Nightly News*, “AIDS Babies” February 11, 1987, VTNA; Stengel “Changing Face of AIDS”

other stories about struggling cities and urban communities. The same month in *Time*, published “The Changing Face of AIDS,” Americans also encountered an article in the magazine titled “The Ghetto: From Bad to Worse,” which reflected on the twentieth anniversary of the 1967 uprisings in cities such as Detroit and Newark. The authors wrote that “Americans cling to the sanguine faith that some magic formula can end this cycle of poverty and social pathology.”²¹⁶

For some healthcare professionals, however, they saw persistent cultural ignorance about the problem of pediatric AIDS, which prompted them to speak out. Dr. Margaret Heagarty became frustrated by what she saw as the lack of significant public attention paid towards children with HIV-AIDS. In an article for *Newsday* in June 1987 which focused largely on the boarder baby issue, Heagarty said: “there has been considerable whoop-de-do about heterosexual transmission because of the people in Larchmont [an affluent suburb of New York City] who [were] concerned that the virus is going...there. But they have leapt right over the kids I’ve got here [in Harlem Hospital].”²¹⁷

Some of Heagarty’s concerns may have been slightly assuaged when a cover story in *Newsweek*, focusing on children with AIDS, was published in the fall of 1987. The

²¹⁶ Walter Shapiro and Jack E. White, “The Ghetto: From Bad to Worse,” *Time*, August 24, 1987. The authors of the *Time* article also suggested that: “Twenty years of failed programs, from community development to public housing, point to a depressing conclusion: little will be done to make the ghetto an acceptable place to live and raise children This by no means suggests abandoning those trapped in the inner city. Rather, the emphasis of both government and private philanthropy must be on helping the black underclass escape the social isolation of these inner-city wastelands.” The point here, however, is how the narratives about inner-city communities continued to use the language of “cycle of poverty” and “social pathologies.”

²¹⁷ Catherine Woodard, “Harlem Hospital’s Lonely Battle with AIDS,” *Newsday*, June 21, 1987. For more details about Heagarty’s experiences with HIV-AIDS patients, see also: Margaret Heagarty, M.D., Oral History, Interviewed by Gerald Oppenheimer, February 8, 1995, Physicians and AIDS Oral History Project, Columbia Oral History Research Office, Columbia University, New York, NY.

article, “Kids with AIDS,” was the first time a major news magazine published a cover story about pediatric AIDS. The story follows a family in the Bronx as they cope with the disease. Two of the toddlers, Celeste and Eddie, were born with HIV-AIDS; their mother died from AIDS in 1983, and their father was struggling to live with the disease. The children lived with their grandmother, Toy. The grandmother also wanted the story to feature the real names of the children because, as the article states, she “wanted readers to see their faces.” The article also echoed other emerging voices on the topic when the author wrote how children “with AIDS have no lobby in Washington. They have no way to raise money they need for their care.”²¹⁸

The *Newsweek* article attempted to highlight the overshadowed story of children born with AIDS, which included the urban conditions in which the children lived. The wooded park across the street from the family’s apartment was “like much of the Bronx, rotten with drugs and violence. Crack vials litter the park’s asphalt paths.” In the building, “junkies gather[ed] on the fifth-floor landing outside Toy’s apartment, while they wait to go up the roof, a favorite spot to shoot up.” In one image, Eddie is shown in his backyard, which was encircled by dilapidated brick buildings in a “decaying, drug-ridden neighborhood” which was part of a “community that appear[ed] bent on self-annihilation.” The article also reminded readers about the potential, higher numbers of pediatric AIDS in the near future. Citing health care professionals, the article showed that the country could see ten thousand to twenty thousand cases of pediatric AIDS by the beginning of the next decade. It also attempted to remind readers of the social, economic,

²¹⁸ Terence Monmaney, “Kids with AIDS,” *Newsweek*, September 7, 1987, 51-59. Note: Celeste is featured on the cover of the magazine, and “Kids with AIDS” was the cover story.

and environmental conditions that led to and exacerbated the problem of pediatric AIDS.²¹⁹

Of note, those popular media accounts reveal that the inner city became an important character in the growing public discourse about pediatric AIDS in the late 1980s. Not only was that evident in the depiction of Eddie’s Bronx neighborhood, but it was also seen in CBS’s long-form news program, *48 Hours*. In October 1988, they aired “In AIDS Alley,” which focused on how the intersection of illicit drugs — both crack-cocaine and heroin — and HIV-AIDS had become a particularly pernicious problem in some American cities.²²⁰ The program took viewers from the shooting galleries of Harlem to the wards of Harlem Hospital. There, powerful images of children sickened by AIDS were cared for Black nurses and pediatricians like Elaine Abrams. Dr. Janet Mitchell, an African-American OBGYN physician who worked with many of the women that gave birth to HIV-AIDS-positive children, told the reporters that she was frustrated by the lack of attention her poor, female patients received before AIDS appeared. “I’ll tell you what hurts me most,” she said, “is why it took AIDS to make people finally focus on this population...I mean, I’ve been taking care of this population all my career.” But those mothers were not shown with their children (if they had, in fact, given birth to HIV-positive infants). The news program — which was one of the few that spent considerable time discussing how AIDS affected children of color — separately showed how the combination of drug use and HIV affected women and children. Most importantly, “In AIDS Alley,” which began its journey in an inner-city shooting gallery, ended by

²¹⁹ Monmaney, “Kids with AIDS.”

²²⁰ CBS News, *48 Hours*, “Inside AIDS Alley,” *48 Hours*, CBS News, October 13, 1988, VTNA.

showing the pediatric ward of Harlem Hospital. The clear message in “AIDS Alley” was that children were “innocent victims” of HIV *and* IV-drug use.²²¹ Such narratives about “pathological” places, and the HIV-positive children they produced, remained important components in national conversations about pediatric AIDS as the federal government responded to the problem.

AIDS Becomes a “Family Disease”

In a speech he gave in April 1987, Regan’s Conservative Surgeon General, C. Everett Koop, argued that pediatric AIDS was closely tied to a particular phenomenon found among poor women of color. First, he did not shy away from explicitly framing some women, and especially children, as “innocent victims” of HIV-AIDS. But he then pivoted to what he saw as an important underlying cause of HIV-AIDS among those victims. “What we are seeing,” he told the audience in San Francisco, is the “tragic evidence of the demography of high-risk pregnancies and birth.” In the United States, he claimed, such pregnancies were more prevalent among Black women, under nineteen, “who were poor...who were not ready for the world of work,” who were under-educated, who were unaided by society to help “control their own sexuality and their destinies,” and, “for whatever reason,” did not have ready access to good prenatal or perinatal care.²²²

²²¹ “Inside AIDS Alley.”

²²²Address by C Everett Koop, Surgeon General of the U.S. Public Health Service and Deputy Assistant Secretary of Health U.S. Department of Health Services, Presented at the Annual Meeting of Education Writers Association, San Francisco, California, April 4, 1987, Box 148, Folder “Introduction to AIDS Archive, 2004-2005,” C. Everett Koop Papers 1933-2011, History of Medicine Division, National Library of Medicine, Bethesda, MD (hereafter cited; Koop Papers). The same month, Koop held his Workshop on Children with HIV. There, a working group discussed and recommended ways to avoid framing children

Here we see that for Koop, and other like-minded Americans, the disintegration of the American family was the root cause of the problem. When considering Koop's views, we must recognize that he was a complicated public figure. Though he held Conservative political and religious views, many Americans that disagreed with his politics nonetheless praised him for his rational, scientific approach towards educating the public about HIV-AIDS.²²³ But as he began to speak publicly about AIDS in the late 1980s, his Conservative views about "the family" influenced how he understood the underlying social factors that led higher rates of pediatric AIDS among certain American families. He told that same crowd in San Francisco that, if people just concentrated on the numbers, they would "miss the true meaning" of HIV-AIDS among children and their families. What is "going on," he told the crowd, "is the profound dysfunction of family life that is taking place among a significant number of our fellow Americans."²²⁴

(or others) as innocent victims of HIV-AIDS. One of the recommendations that emerged from the report was the formation of a non-governmental panel that would address how information about pediatric AIDS was disseminated in the news media or other media. The working group at the workshop, the Health Information Issues and Role in the Media (HIIRM), suggested the proposed group or panel could inform the public discourse about pediatric through the creation of a "style book" to "address the use of ambiguous ("sexually active"), judgmental ("promiscuous"), or stigmatizing ("innocent victims") language." Responding to the recommendations, Koop defended his use of innocent victims when describing children with AIDS. Aware of the politics and potential problems in framing some people with HIV-AIDS as innocent victims, Koop emphasized that he was careful in choosing his language when discussing the disease publicly. He also apologized if he offended anyone in choosing particular language when speaking publicly about the epidemic. However, he argued that using words like innocent victims in publicly discussion pediatric AIDS was a deliberate attempt to try and "attract the attention of others." He continued stating that "I use the words 'innocent victim'...not to indicate that others are not innocent. It is meant to attract attention, especially of those in our society would consign all persons with AIDS to outer darkness." At present, it is unclear if he tried to change his language in public venues after he left his post as Surgeon General. See: Dr. Benjamin K. Silverman and Mr. Anthony Waddell, eds, *Report of the Surgeon General's Workshop on Children with HIV Infection and Their Families* (Washington: U.S. Department of Health and Human Services, 1987): information and quotes from HIIRM are derived from 46; Koop's quote is derived from 73.

²²³ Brier, *Infectious Ideas*. To date, Brier provides us with one of the better, nuanced analyses of the Reagan Administration's response to the epidemic, especially Koop's role in those efforts. See her chapter: "What Should the Federal Government Do to Deal with the Problem of AIDS?" 78-121.

²²⁴ Speech to the Annual Meeting of Education Writers Association, Box 148, Folder "Introduction to AIDS Archive," Koop Papers

Notably, Koop's remarks reveal an important political divide that persisted through, and structured, the emergence of the family-disease framing. It emerged within the context of contentious national conversations about the underclass, "family values," single-motherhood, and urban communities of color beset by a growing number of crises.

Pediatric AIDS advocates sympathetic to the structural causes of HIV-AIDS underscored how the linked problems of poverty and AIDS resulted in the death of families, rather than blaming the particular cultural behaviors which conservatives had framed as the root of the problem. Here, the family was not implicated in the persistence of urban poverty and its related problems. Framing AIDS as a family disease represented a subtle expansion of the innocent victim narrative, which was often used to describe the unfortunate fate of sick and dying children. For those advocates, the death of families, particularly single mothers and their children, represented an unfortunate consequence of urban poverty.²²⁵

That was evident in the political and policy discussions about how the federal government should respond to pediatric AIDS. On July 27, 1987, a Congressional hearing was held at Harlem Hospital specifically focused on pediatric AIDS. In his opening statement, Representative Benjamin Gilman (R-NY) stated that children who have become known as "AIDS babies" was a "real tragedy" in need of a resolution. "Most of the tiny babies," he stated, contracted the disease "while still in their Mother's womb." Mothers, he continued, that contracted the disease from illicit drug abuse or by

²²⁵ Information about the politics of poverty is informed by: Katz, *The Undeserving Poor*; Katz, *Why Don't American Cities Burn?* For the politics of the family and "family values," see: Bruce J. Schulman and Julian E. Zelizer, eds., *Rightward Bound: Making America Conservative in the 1970s* (Cambridge, Mass: Harvard University Press, 2008); Robert O. Self, *All in the Family : The Realignment of American Democracy since the 1960s*, 1st edition. (New York : Hill and Wang, 2012); Kevin Michael Kruse, *Fault Lines: A History of the United States since 1974*, 1st edition, (New York: W.W. Norton & Company, 2019).

“a sexual act.”²²⁶ Two years later, On February 22, 1989, Representative Ted Weiss (D-NY) mentioned in his opening remarks at a Congressional hearing titled *Children with HIV Infection* that “AIDS is frequently the final assault on a family that is poor and facing numerous problems.” He continued stating we “cannot sit idly by as these children become ill and die,” and are orphaned because “their parents become ill and die.”²²⁷

The different depictions of the problem represent an important pivot in how some tried to reframe discussions surrounding AIDS among children and their families.

Gilman’s remarks recognized that families were affected by AIDS, with an emphasis on how children “innocently” contracted the disease from the taboo behavior of a parent, a common political and cultural trope in the U.S. Weiss’s comments, on the other hand, reflected how AIDS had become a “family disease” in some communities of color. As Weiss framed it in 1989: when “a child has AIDS, you are witnessing not only the possible destruction of an individual life, but also the life of a family.”²²⁸

What these different framings of innocent victimhood represented is how pediatric AIDS became a symbol — perhaps even evidence — of who or what was responsible for the disease in poor, urban communities of color. For some, it was the result of poor parental decision-making or the so-called breakdown of the American family. For others, pediatric AIDS represented how poverty and structural inequality

²²⁶ *Pediatric AIDS Hearing, July 27, 1987, before the Select Committee on Narcotics Abuse and Control, House of Representatives, 100th Cong 2 (1987)* (statement of Congressman Benjamin Gilman).

²²⁷ *Children and HIV Infection, Day 1, February 22, 1989, Hearings before the Human Resources and Intergovernmental Relations Subcommittee of the Committee on Government Operations, 100th Cong. 2 (1989)* (statement of Congressman Ted Weiss). Rep. Weiss’s reference to the “assault on the family” was in a press release about the hearing: Congress of the United States, House of Representatives, “News Release, ‘House Panel to Review Federal Actions on Pediatric AIDS,’” Box 129, Folder “Pediatrics 1987-1990” Randy Shilts Papers (GLC 43), James C. Hormel LGBTQIA Center, San Francisco Public Library, San Francisco, CA (hereafter cited; Shilts papers) .

²²⁸ *Children and HIV Infection, 2.*

helped cause and exacerbate the problem of HIV-AIDS among families of color. The slight shift in focusing on families reflected a larger phenomenon related to how pediatric AIDS was framed by the politics of the family in U.S., and how its political visibility challenged longstanding narratives about innocent victimhood.

Of course, there was inherent political utility in relying on innocent victim tropes for federal officials in their response to pediatric AIDS. In July 1987, Representative Major R. Owens (D-NY) introduced a bill titled “The Abandoned Infants Assistance Act of 1987” as a “modest attempt to rescue the hundreds of innocent young lives,” who were orphaned in city hospitals because of the epidemic.²²⁹ Receiving bipartisan support, the legislation was passed in 1988 and was the first significant federal legislation to directly address pediatric AIDS. The law appropriated \$37 million (to be disbursed between 1989 and 1991) to develop demonstration projects that not only sought to recruit and support foster families, but also to help prevent continued orphaning of children in hospitals. While the bill was debated, some pediatric health professionals thought the funds too large. In his testimony before Congress, Surgeon General Koop, who was a pediatric surgeon, thought \$1.2 million a was “a reasonable sum” because, he added, “we must all make decisions about where Government money should be spent.” Nevertheless, the still-modest sum of \$37 million, which also included supporting children orphaned by parental drug use, was certainly helpful for some health care and foster facilities in the U.S. when the funds were finally disbursed in 1990.²³⁰

²²⁹ Rep. Major R. Owens, “The Abandoned Infants Assistance Act of 1987,” 133 *Congressional Record* E 3060, July 23, 1987, Vol 133, Pg 122, Cong Sess. 100-1.

²³⁰ Details about the legislation is derived from the following: Abandoned Infants Act of 1988, Pub. L. No. 100-505, 102 Stat. 2533 (1988); “Public Law 100-505, Abandoned Infants Assistance Act of 1988, 18

In 1988, as HHS began to grapple with pediatric AIDS, an internal memo also used the language of innocent victimhood in creating their Pediatric AIDS Initiative. Secretary of HHS Otis Bowen wrote: "Pediatric AIDS is a tragic and growing problem. Small children are innocent victims of this terrible epidemic. While the numbers are still very small... the tragedy of their young lives requires us to take action."²³¹ The formation of the Pediatric AIDS Initiative eventually produced one of the first comprehensive reports about pediatric AIDS, the *Final Report: Secretary's Work Group on Pediatric HIV Infection and Disease* (1988).²³² In addition to detailing the many healthcare problems related to pediatric AIDS the report also cited the possibility of ten thousand to twenty thousand cases of pediatric AIDS by the early 1990s.²³³ The language of innocent victimhood may have been a perfunctory way of describing sick and dying children among healthcare professionals, but the prospect of higher numbers of cases seemed to be an important point of concern for federal health officials.

As elected officials sought to pass the first comprehensive law to fund all AIDS-related care initiatives, we see how they used HIV-AIDS among women and children to make their case for a government-funded initiative. In passing the Ryan White CARE Act (1990), roughly 20 percent of the Congressional hearings were devoted to how AIDS

October 1988," *Annual Review of Population Law* 15 (1988): 125–26; *Field Hearing on the Abandoned Infants Assistance Act, May 10, 1991, Hearing before the Subcommittee on Select Education of the Committee on Education and Labor, House of Representatives, 100th Cong.* (1991); *H.R. 3009, the Abandoned Infants Assistance Act of 1987, October 22, 1987, Hearing before the Subcommittee on Select Education of the Committee on Education and Labor, 100th Cong.* 1-134 (1987).

²³¹ Memo to Heads of Operating Divisions and Heads of Staff Division, From The Health and Human Services Secretary, Dr. Otis Bowen, subject, "Pediatric AIDS Initiative," Box 61, Folder "Pediatric AIDS Initiative," Koop Papers.

²³² Antonia C. Novello *Final Report : Secretary's Work Group on Pediatric HIV Infection and Disease* (Washington DC: Department of Health and Human Services, 1988)

²³³ See: Bowen memo, "Pediatric AIDS Initiative" and Novello, *Final Report*, 7.

affected children and young people.²³⁴ In one report, *A Generation in Jeopardy: Children and AIDS* (1988), which was referenced in the lead-up to the law's passage, federal officials stated that while "the numbers of children who have AIDS...remain low, they are increasing...consequently, the threat must be taken serious." The same report cited the possibility of ten thousand to twenty thousand cases by the early 1990s. In addition, many of the children referenced in the report were Black or Latinx, and had acquired the disease perinatally²³⁵ Of course, using "innocent victims" as evidence for passing the law was one successful and decades-old strategy used by elected officials.²³⁶ African American elected officials, on the other hand, also leveraged pediatric AIDS beyond attempting to pass needed AIDS-related legislation.

For elected black officials, the trope of innocent victimhood was part of a strategy to discuss the problem of HIV-AIDS affecting the communities they represented. Political scientist and African American studies scholar Cathy Cohen provides a comprehensive and critical analysis of the response to the epidemic among Black leaders. According to Cohen, through "the frame of children, representatives were able to work on the issue of AIDS without the baggage that traditionally comes with this issue," namely homosexuality and illicit drug use.²³⁷ The latter was a particularly complicated issue for national black leaders because many other Americans narrowly perceived illicit drug use as an endemic social problem among African Americans. As the legal scholar Harlon L. Dalton suggested in 1989, openly discussing the link between drug use and

²³⁴ See, for example: Cohen, *The Boundaries of Blackness*, 293-338; Siplon, *AIDS and the Policy Struggle in the United States*, 93-134.

²³⁵ Select Comm. on Children, Youth, and Families, *A Generation in Jeopardy Children and AIDS*, H.R. Rep. No 80-284 (1988); quote derived from VII.

²³⁶ Siplon, *AIDS and the Policy Struggle in the United States*.

²³⁷ Cohen, *The Boundaries of Blackness*, 325.

AIDS posed a tricky dilemma for Black leaders. On the one hand, they felt the need to highlight how drug use was both a pernicious problem in some Black communities *and* a major factor spreading HIV in those same places. On the other hand, drawing attention to the linked problems of drugs and AIDS invited further public scrutiny about illicit narcotic use among African Americans — a complex problem few white Americans understood — thus potentially reinforcing negative stereotypes about how the inner city and its residents were somehow inherently “pathological”.²³⁸

Pediatric AIDS thus presented Black elected officials a way to shift the conversation about AIDS towards systemic issue related to the disease, rather than focusing on questions about particular behaviors of individuals. A case in point is the *Pediatric AIDS* hearing held in Harlem in the summer of 1987. Congressman Charles Rangel (D-NY), opened the hearing stating, “[o]ne might question why a Select Narcotics Committee would be...[dealing] with the problem of [AIDS in] children.” For Rangel, it was an opportunity to further highlight the deleterious effects drug use had on communities of color in New York City and in other parts of the country. But other testimony during the hearing spoke to how pediatric AIDS was a direct consequence of larger structural issues that have been a problem in Black communities for decades. Then–Manhattan Borough President David Dinkins testified that “AIDS does not exist apart from other chronic problems we face in our cities...poverty, drug abuse, limited access to health care, the housing shortage, discrimination, illiteracy and other barriers to AIDS prevention and treatment,” all of which, he continued, needed to be addressed if

²³⁸ Cohen, *The Boundaries of Blackness*, 293–332. For the ways in which black leaders were reluctant to “own” the AIDS epidemic, especially as it related to IV drug use, also see: Harold Dalton, “AIDS in Black Face,” in “Living with AIDS: Part II,” *Daedalus* 118, no. 3 (Summer 1989): 205-227.

AIDS prevention and care was to be successful. Rangel seconded Dinkins' remarks, stating myopic approaches to the problem would be "Band-aid[s]" if the larger structure issues were not addressed.²³⁹

Dinkins also discussed how pediatric AIDS represented the impact the disease had on the family. "This is a health crisis, and the responsibility for addressing it rests with all of us," he said. Most importantly, he stated that when considering "the impact of AIDS on children, what we are really addressing is the impact of AIDS on heterosexual families." His comments were directed towards helping prevent HIV-AIDS among women and their sexual partners, as a way to thus prevent pediatric AIDS. Though unintentional, we see how the narrative of innocent victimhood was beginning to incorporate the family in national political discussions about HIV-AIDS.²⁴⁰

Conversely, pediatric AIDS advocates, especially health care professionals, referenced the impact of AIDS on families to publicly challenge popular perceptions about innocent victimhood. In December 1987, before the Reagan Administration's Commission on the HIV epidemic, Dr. Heagarty told a moving account about one of her deceased patients, and the struggles the family faced [Image 4]. The mother was an IV-drug user and the father an alcoholic, she stated. Heagarty was, however, emphatic when she qualified her statement about the particular family. "Despite their very real limitations and personal tragedies, she said, "they tried in their own way to love and support the child." With a slight pause in her statement, a stern voice, and an austere glance towards

²³⁹ *Pediatric AIDS*, July 27, 1987, *Hearing before the Select Comm. on Narcotics Abuse and Control, House of Representatives*, 100th Cong. 1, 47, and 53 (1988); quotes derived from 1,47,and, 53 respectively.

²⁴⁰ *Pediatric AIDS*; quote derived from 48; See also: Cohen, *The Boundaries of Blackness*, 329. Cohen also makes the point that black elected officials often skirted conversations about homosexuality in their public remarks about HIV-AIDS.

the Commission members, she told her audience: "So let me be clear, I and my staff do not judge these parents, nor do we condemn them — nor may you."²⁴¹



Image 4: Dr. Margaret Heagarty at Hearing for President Reagan's Commission on AIDS, 1987

Others alerted federal officials to the social and economic conditions that structured and constrained the agency of women who were vulnerable to HIV infection. In a letter to the Government Accounting Office during the summer of 1988, Oleske explained how non-IV-drug using women were at risk of contracting the disease through sexual contact, because they were often unable to refuse sex or demand a partner use protection. “Many of the women are in oppressed relationships,” he wrote, “and are dependent on their male partners for financial survival and support of children.” Therefore, he continued, it was not in the woman’s “best interest to ask too many

²⁴¹ Transcript: Presidential Commission on the Human Immunodeficiency Virus Epidemic, Hearing on IV Drug Use, December 19, 1987, Box 1, Folder, IV Drug Abuse and HIV Hearings, December 17-19, 1987, National Commission on Acquired Immune Deficiency Syndrome, National Commission Papers. At least some of the hearing were televised on C-Span. See: “AIDS and Intravenous Drug Use, Presidential Commission on Human Immunodeficiency Virus Epidemic,” accessed July 1, 2017, <https://www.c-span.org/video/?927-1/aids-intravenous-drug>. The image of Heagarty is also derived from the televised coverage of the hearing on C-Span.

questions or to become assertive within their relationship.”²⁴² In 1989, Boland told Congressional leaders that 40 percent of the women they saw in Newark contracted the disease sexually. Those women, she said, were not IV-drug users, nor were they “prostitutes.” They were “often in monogamous — so they think — relationships. Their risk comes from their sexual partner. Many of them [were] poor, single-parent working women in the inner city striving for a better life for themselves and their families.”²⁴³

By 1989, the tone in public conversations about pediatric AIDS had shifted towards more explicit references to how AIDS was a disease affecting the entire family, not just children. At a Congressional hearing in 1989, Dr. Janet Mitchell framed the family-disease effect in a way that directly challenged the language of innocent victimhood often used to describe children with the disease. “They [children] are seen as ‘innocent victims,’” she said, but such language “divorce[d] that child from the fact they did come from a family.”²⁴⁴ The persistence of urban poverty also structured the emergence of the family-disease framing. On February 6, 1989, the *New York Times* published an article titled, “Inner City Under Siege: Fighting AIDS in Newark.” The story illustrated how the disease had “reached deeply” into poor, urban communities of color, “devastating...families already overwhelmed with social and medical ills.”

Newark, as it had since the 1960s, stood as a symbol of neglect and urban decay. Wayne

²⁴² Letter from Dr. James Oleske to Eric Larson, Program Evaluation Methodology Division, GAO, July 26, 1988, Oleske Personal Papers.

²⁴³ *Children and HIV Infection, Day 1, February 22, 1989, Hearing before the Human Resources and Intergovernmental Relations Subcommittee of the Comm. on Government Operations, 101st Cong. 31* (1989) (statement of Nurse Mary Boland); quote derived from 32.

²⁴⁴ *Children and HIV Infection, 26* (statement of Dr. Janet Mitchel); quote derived from 74. Other public health and health care professionals made the point of underscoring, publicly, how AIDS was killing families: see, for example, Transcript: Public Hearing before Assembly Health and human Resources Committee to Examine Policy issues relating to Acquired Immune Deficiency Syndrome (AIDS), February 19, 1989, State House Annex, Trenton, New Jersey, Box 11, Folder 16, NJ AIDS Collection.

Duncan from the National Minority Outreach Initiative at the CDC said that in “cities like Newark, AIDS has become a disease of the family...[w]e’re talking about women, children, men. It’s not skipping over anyone.”²⁴⁵ Talking to reporters that same year, Oleske stated that “AIDS is just the end of a long list of things that can happen” [to families living in poverty]...AIDS in children is a family disease. Children get sick and die, and so do their mothers and fathers.”²⁴⁶

The connection between poor urban communities and the family-disease framing can be read as a reaction to the politics of poverty that arose during the Reagan years. A *Washington Post* article in January 1989 spoke of one Reagan legacy : the “medical underclass.” The author wrote that one of the unfortunate consequences of the “Regan revolution” was a growing medical underclass that included “AIDS babies and crack newborns in overwhelmed pediatric wards.” Writing about AIDS and TB, for example, the author wrote, “[p]overty and minority status are clearly linked to these diseases.”²⁴⁷ In that context, references to AIDS as a family disease was an attempt to shift the focus to underlying causes of the disease. At a Congressional hearing in 1990, Boland mentioned how urban “communities that suffer with drug use, poverty, inadequate housing and poor access to health care have emerged as the epicenters of the epidemic in women and children.”²⁴⁸

²⁴⁵ Lena Williams, “Inner City Under Siege: Fighting AIDS in Newark, *The New York Times*, February 6, 1989. In fact, Williams’s article was one of the rare journalistic accounts that captured the complexities of HIV-AIDS in Newark during the late 1980s.

²⁴⁶ Lindy Washburn, “Doctor with a very big heart helps AIDS Littlest Victims,” *The Record*, April 21, 1989.

²⁴⁷ Abigail Trafford, “The Reagan Legacy: A Swelling Medical Underclass in a Land of Plenty,” *The Washington Post*, January 24, 1989.

²⁴⁸ *Pediatric AIDS, March 13, 1990, Hearing before the Task Force on Human Resources of the Committee on the Budget*, 101st Cong. 31 (1990); quote derived from 100.

Framing AIDS in such a way provided policymakers and healthcare professionals a tool for illuminating the combined problems of racial and economic inequality that many urban families of color faced. In a 1988 Congressional report, *Continuing Jeopardy: Children and AIDS*, Oleske is quoted, saying: “AIDS is a disease of poverty and drug abuse.”²⁴⁹ Discussants before the Reagan Administration’s Commission on the epidemic drew federal officials’ attention to the problem of poverty and HIV.²⁵⁰ The *Report of the Presidential Commission on [HIV]* (1988), for example, explicitly discussed that HIV-AIDS among IV drug users and their children was “disproportionately” affecting the nation’s “underclass.” Referencing William Julius Wilson’s book, *The Truly Disadvantaged*, the Presidential Commission’s report argued that it was “imperative that this nation recognize and address the context in which the epidemic is occurring.” Specifically, they noted, that disease was endemic where the persistence of poverty engendered “hopelessness and despair which can only lead to heroin abuse.”²⁵¹ And in a special issue of *The American Journal of the Disease of Children* (1990), which focused on the intersection of poverty and childhood illness,

²⁴⁹ Select Committee on Children, Youth, and Families, *Continuing Jeopardy: Children and AIDS*, H.R. Rep. 88-650, (1988); quote derived from 10.

²⁵⁰ See, for example, Transcript: Mary G. Boland’s testimony before the Commission: “Presidential Commission on the Human Immunodeficiency Virus Epidemic, Hearing on Care of HIV-Infected Persons, Wednesday, January 13, 1988,” 56, Box 1, Folder, “Care of HIV Infected Persons,” National Commission Papers.

²⁵¹ Presidential Commission on the Human Immunodeficiency Virus Epidemic, *Report of the Presidential Commission on the Human Immunodeficiency Virus Epidemic : Submitted to the President of the United States*. (Washington : The Commission on the Human Immunodeficiency Virus Epidemic, 1988); quote derived from 93. Here, the Commission was directly referencing Wilson’s *The Truly Disadvantaged*.

Heagarty claimed that "most children with AIDS and their families come largely from the most socially disorganized, economically deprived segments of our society."²⁵²

For those health professionals, poverty was one of the most problematic underlying cause for HIV-AID in children specifically, and in communities of color more broadly. In 1991, while addressing the National Hispanic Conference on Substance Abuse, Antonia C. Novello, the George H.W. Bush administration's Surgeon General, talked about the poverty-related health problems. "To name a few," she stated, "we have problems with poverty, lack of health services, addiction to drugs and alcohol, and AIDS." Speaking specifically of HIV-AIDS, she told the meeting that "[m]ore and more, HIV infection has become a disease confronting the young, the heterosexuals, and the children and women. It has become a family issue."²⁵³

Though other Americans did not deny that poverty was a problem for those families, they may not have agreed that pediatric AIDS was *the* direct consequence of urban poverty. In a piece in the *Washington Post*, titled "Heroin and AIDS: Deadly Mix for Blacks," one author opined about the continued and growing problem of AIDS among communities of color. Speaking about the death of the widely known Black journalist, Max Robinson — who had died of AIDS — the author wrote, "nothing, not the death of celebrities or the demise of countless, nameless souls, has affected the increasingly self-

²⁵² Margaret Heagarty, "Pediatric Acquired Immunodeficiency Syndrome, Poverty, and National Priorities," *American Journal of Disease of Children* 145, no. 5 (1990): 527-528; quote is derived from 527.

²⁵³ Antonia C. Novello, "Adelante Con Confianza," Keynote Address, "Addressing the National Hispanic Conference on Substance Abuse, Prevention, Treatment, and HIV/AIDS, September 6, 1991, MSC 818, Box 1, Folder 39, June Osborn Papers, History of Medicine Division, National Library of Medicine, Bethesda, MD; quotes derived from pages 3 and 6 of speech, respectively.

destructive behavior of black American.”²⁵⁴ Here, we can see the continued influence of the “culture of poverty” narrative, which manifested in discussions about the underclass and HIV-AIDS.

Such cultural-behavioral analyses about the prevalence of HIV-AIDS among the “underclass” is also important when considering the emergence and use of the family-disease script. On the one hand, people who framed AIDS as a “family disease” constructed a counter narrative that challenged popular perceptions about urban poverty — a popular perception that had persisted since least the 1960s — which saw cultural and familial structures as the root causes of the underclass. On the other hand, and most importantly, such challenges could not ultimately penetrate deeply rooted ideas about why and how urban poverty persisted in U.S. inner cities. For some Americans, urban poverty and its related issues — which, by the late 1980s, included AIDS — was unequivocally the result of one’s personal failings, which were tied to cultural and behavioral phenomena found among the urban “underclass.”²⁵⁵ The controversial Conservative Congressman from California, William Dannemeyer, perhaps offers a blunt summation of such attitudes. In a letter to the Assistant Secretary for HHS, Dr. Robert E. Windom, the Congressman inquired about the likelihood of AIDS becoming a problem among heterosexuals. “In preparing your answer,” Dannemeyer wrote, “please distinguish between heterosexual transmission in our drug-blighted inner cities and

²⁵⁴ Courtland Milloy, “Heroin and AIDS: Deadly Mix for Blacks,” *The Washington Post*, January 10, 1989. Max Robinson’s life with and death from AIDS was also discussed on network news, see: “Robinson Death,” *NBC Nightly News*, December 20, 1988, VTNA.

²⁵⁵ Katz, *The Undeserving Poor*, 124–235. Katz does not discuss the links between HIV-AIDS and the underclass, but I am using his work to inform my analysis.

heterosexual transmission elsewhere.”²⁵⁶ For Americans that agreed with Dannemeyer’s assessment, AIDS may have been a “family disease,” but those families were responsible for, rather than victims of, the “drug blighted inner cities” in which they lived.

The Politics of Representation – Whose Family?

In the late 1980s, two movies aired on television depicting young Americans with HIV-AIDS. The biographical, made-for-TV movie that Oleske agreed to make back in 1985 finally aired in April of 1989. By that point, the name changed. Originally titled *The Innocent Victims*, Oleske insisted on changing the name at some point after 1987 to *The Littlest Victims*.²⁵⁷ In many ways, that tracked with how Oleske publicly spoke about pediatric AIDS. As a way to draw attention to the problem in 1984, he explicitly called children with AIDS “innocent victims.” By 1989, as he told a reporter after the movie debuted, people with the disease “are all innocent victims.” Though the movie acquired a new title, an innocent-victim narrative structures the plot. In *The Littlest Victims*, the plot follows Oleske as he struggled to care for his patients, fought to secure federal funding, and grew increasingly frustrated that few Americans, especially those in the government, did not seem to care about children with AIDS. The city of Newark is only mentioned in the beginning, and the viewer does not get a sense of the urban landscape outside the walls of the hospital. Families were virtually absent as well, save for a few scenes that depicted stepparents who cared for a child with AIDS, and a mother who gave birth to a

²⁵⁶ Letter from William Dannemeyer to Dr. Windom, February 7, 1989, Box 54, Folder, “Sequential File,” Koop Papers.

²⁵⁷ Letter to James M. Oleske, from Anne Carlucci, December 3, 1987, Dr Oleske’s Personal Papers. According to this letter, the title of the movie was still *The Innocent Victims* by the end of 1987. The reference to Oleske’s claim that he insisted on changing the title is derived from: Kathryn Baker, “First Made-for-TV Movie with HDTV, *The Desert News* (Salt Lake City), April 22, 1989.

child with HIV. The latter was named Estelle, an ex-drug user and prostitute who, after losing her child to AIDS, returned to prostitution. In the end, however, *The Littlest Victims* was the only movie about HIV-AIDS in the 1980s that featured Black children.²⁵⁸ “I congratulate CBS in making a movie that shows...the real story,” Oleske told a reporter, “that most young victims of AIDS are minority children of poverty-stricken parents.”²⁵⁹

Oleske’s remarks came roughly three months after *The Ryan White Story* aired on TV in January 1989, and his comments seem to be subtly critiquing the film. Ryan White was the most recognizable and celebrated young American with AIDS by that point. Both movies, moreover, were part of a made-for-tv-movie genre that cultural studies scholar Paula Treichler, calls “disease-of-the-week” stories.²⁶⁰ But the difference between *The Ryan White Story* and *The Littlest Victims* is telling when considering which families became the public face of AIDS. The movie about Ryan White opens with a montage of Indiana images such as the Indiana Dancer’s Association, football fans, farms, small homes, and war memorials, all accompanied by John Cougar Mellencamp’s “Small Town.” The story that follows is that of Ryan’s struggle with ignorant and sometimes hostile residents of Kokomo, Indiana; his legal struggles surrounding his exclusion from high school; and, of course, his life with AIDS.²⁶¹

²⁵⁸ *The Littlest Victims*, directed by Peter Levin, written by J.J. Towne and Kenneth Cavander, aired April 23, 1989, accessed January 1, 2017, <https://www.imdb.com/title/tt0097760/>.

²⁵⁹ *The Littlest Victims*

²⁶⁰ Treichler, *How to Have Theory in an Epidemic*. I am specifically referring to her chapter “AIDS Narratives on Television.” She does not, however, discuss “The Littlest Victims.”

²⁶¹ *The Ryan White Story*, directed by John Herzfeld, written by Phil Penningroth and John Herzfeld, aired January 16, 1989, accessed January 1, 2017, <https://www.imdb.com/title/tt0098237/>.

Yet at the center of the story is Ryan and his family. The movie shows how his single mother not only cared for the chronically-ill Ryan, but for his sister as well. Where Newark was largely invisible in *The Littlest Victims*, middle-American life was an important character in *The Ryan White Story*.²⁶² The contrasting use of place in the films also further reveals the cultural imaginaries that structured the way some Americans saw HIV-AIDS among young people. The absence of Newark (as a character) in *The Littlest Victims* showed how unimportant the city was in telling that version of the story, except for the few characters many white Americans would have recognized: an IV-drug-using father, an ex-drug-using prostitute mother, and some men rolling dice outside the hospital.²⁶³

Around the same time, Elizabeth Glaser was making her debut as one of the most well-known pediatric-AIDS advocates in the United States. Married to Paul Michael Glaser — known for his role on the TV show *Starsky and Hutch* — Elizabeth acquired HIV-AIDS through a blood transfusion: both of her children were subsequently infected as well. From around 1988 to 1992, Glaser was “avidly covered” in the news media, helped raise money for pediatric AIDS, testified before Congress, spoke at the Democratic National Convention (1992), and co-founded the Pediatric AIDS Foundation.²⁶⁴ In her memoir *In the Absence of Angels* (1991), she felt compelled to speak out about pediatric AIDS, because “[n]o one was fighting for children. No one. I felt a mantle of responsibility descend over my shoulders. It was a frightening and

²⁶² *The Ryan White Story*

²⁶³ *The Littlest Victims*

²⁶⁴ Barron Lerner provides a good history about Glaser and how she leveraged her privileged position to become an influential spokesperson for pediatric AIDS. Barron H. Lerner, *When Illness Goes Public: Celebrity Patients and How We Look at Medicine* (Baltimore: Johns Hopkins Press, 2006); quote derived from 235.

unforgettable moment.”²⁶⁵ In her impassioned speech at the Democratic National Convention in 1992, she made a plea to all Americans to consider those, like her, who were struggling with AIDS. She even recognized that her role as a pediatric-AIDS spokesperson, “a well-to-do white woman” was contrary to the reality of who was most affected by pediatric AIDS: women and children of color.²⁶⁶

Also in the summer of 1992, the accomplished and wealthy white woman, Mary Fisher, spoke before the Republican National Convention (RNC) about her experience with HIV-AIDS. She acquired the disease from her husband, and she spoke to the crowd about how the Republic party should support President George H.W. Bush’s efforts to address the epidemic. The politics of family values certainly informed part of her message. She told the audience, “[w]e do the President’s cause no good if we praise the American family, but ignore a virus that is destroys it.” She provided no specifics about which families she was referring to.²⁶⁷

Several months later, in December 1992, HIV-AIDS healthcare professionals held a workshop in Newark titled, *AIDS as a Family Disease*. The workshop was not solely devoted to the care of children and their families; it covered everything from clinical-care practices, to HIV-education dissemination, to long-term care issues. In her opening

²⁶⁵ Elizabeth Glaser, *In the Absence of Angels* (New York : Berkley Books, c1992.); quote derived from 112.

²⁶⁶ Glaser, along with her husband, testified at a Congressional hearing about pediatric AIDS in 1990. *Pediatric AIDS* 101st Cong. 31 (1990). For her DNC speech, see: accessed January 1, 2017, <https://www.youtube.com/watch?v=hK15XLRn3XM>. David L. Kirp, also commented on Glaser’s role as notable spokesperson for pediatric AIDS. He wrote in 1990: "Pediatric AIDS, for several years a back-burner issue, has made its way to the top of the legislative agenda because of a remarkable woman: Elisabeth Glaser..." See: David L. Kirp, “The Politics of Pediatric AIDS,” *The Nation*, May 14, 1990.

²⁶⁷ Mary Fisher’s full speech is available online: see, accessed January 1, 2018, https://www.youtube.com/watch?v=zB5K9k_S0o. Fisher’s quote is derived from her speech. Fisher’s biographical information is provided by, Alice Steinbach, “Addressing AIDS: HIV-positive Mary Fisher Tells GOP about ‘Our’ Disease,” *The Baltimore Sun*, August 16, 1992. She was briefly featured in a segment on the NBC *Nightly News*, “American Close Up, Women and AIDS,” August 20, 1992, VTNA.

remarks, Mathilde Krim, the co-founder of the American Foundation for AIDS Research, spoke about how AIDS had “literally” become a family disease among African American families and African families because it affected mothers, fathers, and children alike. She also spoke to another theme of the workshop that reminded health care workers that “family” had a broader meaning than simply a “nuclear family” or a mother-child dyad. She spoke of a kind of network of “family” members — outside of traditional relationships — that were important in ensuring the care of people with AIDS.²⁶⁸

But Krim’s statements about the potential broader cultural value of the family-disease frame illustrates what some AIDS advocates were hoping this counter narrative would provide. She argued that “families can be great resources in tasks that address the broad aspects of the epidemic: they can put a human face on the epidemic,” which could help “reduce the isolation of others, and fight discrimination. They are powerful advocates for humane public policies, for better funding for care and research and for sensible approaches to education and prevention.” Unaddressed in the speech was how some families were perhaps unable to speak out because of socioeconomic barriers, or were not recognized as the types of families that engendered a broader call to action to help treat and prevent HIV-AIDS in all American families.²⁶⁹ Nevertheless, by the early 1990s, most references to the AIDS as a “family disease” gradually disappeared from the national discourse about the epidemic.

²⁶⁸ The AIDS Education and Training Centers Network, *AIDS As a Family Disease*, Proceedings of the Second Annual Meeting of the AIDS Education and Training Centers, 9-14, Box 12, Folder, 14, NJ AIDS Collection.

²⁶⁹ *AIDS as a Family Disease*; quotes derived from, 13-14.

Though discussions about AIDS as a family disease emerged out of the nation's focus on poor, Black families coping with the epidemic, it is unsurprising the prominent family spokespeople were individuals like Elizabeth Glaser. Her race, class, and connections afforded her the opportunities to raise awareness and money for pediatric AIDS. But, as we have seen, pediatric-healthcare professionals and childhood-welfare organizations were also addressing the problem, and in some cases speaking out publicly. Though pediatric AIDS never gained the type of activist support evidenced by the work of ACT UP, for example, people were "doing something" about pediatric AIDS by the early 1990s, contrary to what Glaser wrote in her autobiography. It was just through the healthcare and policy networks in which pediatric-AIDS advocates operated.²⁷⁰

Nevertheless, despite their statistical marginality, children and families of color affected by the disease were quite visible to the American public, but that visibility was filtered through decades-old narratives about urban poverty. Even if some Americans, who lived outside poor communities of color, were concerned that heterosexual transmission might have placed their families at risk, those notions were certainly put to rest by 1992. In the summer of 1992, as Americans saw Mary Fisher speak at the RNC, NBC *Nightly News* showed Dr. Mary Ann Chaisson from the New York City Department of Health discuss the epidemiology of AIDS among women and children. Unlike in Africa, she stated, high rates of heterosexual transmission of HIV would most likely not

²⁷⁰ Besides elected officials and pediatric AIDS advocates working on issues related to HIV-AIDS in children, children's welfare groups also worked to address the problem. See, for example: Gary R. Anderson, *Children and AIDS: The Challenge for Child Welfare* (Washington DC: The Child Welfare League, 1986); CWLA Task Force on Children and HIV Infection, *Report of the CWLA Task Force on Children and HIV Infection: Initial Guidelines* (Washington DC: Child Welfare League of America, 1988); Paul Gitelson and Jean Emery, *Serving HIV-Infected Children, Youth, and Their Families: A Guide for Residential Group Care Providers* (Washington DC: Child Welfare League of America, 1989).

occur in the U.S. “I think” she said, “it’s going to stay pretty close to neighborhoods where IV drug use and poverty are common.”²⁷¹ Depending on one’s political persuasion, those poor, urban families living with HIV-AIDS were to be pitied as innocent victims or simply ignored.²⁷² Regardless, pediatric AIDS was “elsewhere” in the minds of Americans; it had become, like children born to women that used crack-cocaine, just another problem of “the inner city.”

But those children and families still required care. As pediatric AIDS was gaining a heightened degree of cultural and political visibility, healthcare professionals were operating in well-established systems of care that treated children with AIDS. They long knew that AIDS was a “family disease,” and thus developed a family-centered network of care that became an important system managing and maintaining the health of children with HIV-AIDS.²⁷³ As we will see, nurses were an especially important part of that system.

²⁷¹ “American Close Up, Women and AIDS,” August 20, 1992, VTNA.

²⁷² This is informed by Michael Katz’s analysis of the poverty discourse in the United States during the 1970s and 1980s: see, Katz *The Undeserving Poor*, 209.

²⁷³ See, for example: *AIDS and Young Children in South Florida, August 7, 1989, Hearing before the Select Committee on Children, Youth, and Families*, 101st Cong. (1990) (statement of Dr. Gwendolyn Scott).

CHAPTER 4: “UNTIL A CURE IS FOUND”: SICK CHILDREN AND THE PEOPLE WHO CARED FOR THEM, 1988—1997

By the mid-1980s, nurses Mary Boland and Teresa D.B. Gaskill well understood the techniques needed to manage the health of children with AIDS. In “Managing AIDS in Children,” they provided their nursing colleagues a pithy assessment about the known science of pediatric AIDS, how nurses played an important role in managing the physical and psychological health of children with the disease, and they even discussed how best to deal with the stigma associated with AIDS. At the time, managing opportunistic infections and other health problems was key. Under a section titled, “Until a Cure is Found,” they wrote: “[s]ince AIDS victims cannot be cured at this time, the goal of treatment is to prevent mortality and decrease the high morbidity caused by repeated infections.”²⁷⁴

By the end of the 1990s, the management of HIV in children had vastly improved through the development and use of effective antiretroviral therapies (ARTs). As some pediatric AIDS experts pointed out in 1998, ARTs were an essential tool in the chronic management of HIV, which *also* included supportive care, pain management, proper nutrition, and psychological services.²⁷⁵ But those drugs, while an important life-saving technology, were not, of course, a cure for the disease.

Besides their therapeutic value, the advent of effective HIV treatments represented an important marker in the history of the AIDS epidemic. Standard narratives

²⁷⁴ Mary Boland and Teresa D.B. Gaskill, “Managing AIDS in Children,” *MCN: The American Journal of Maternal/Child Nursing* 9, no. 6 (November/December 1984): 384-389; quote derived from 385.

²⁷⁵ See, for example, Brigitta U Mueller, Mark W. Kline, and Philip A. Pizzo, “Antiretroviral Treatment” in: Philip A. Pizzo and Catherine M. Wilfert, eds., *Pediatric AIDS: The Challenge of HIV Infection in Infants, Children, and Adolescents*, 3rd ed (Baltimore: Williams & Wilkins, 1998), 464.

about the epidemic show that the drugs were a life-saving boon for patients and healthcare practitioners alike, which marked a change in the treatment and clinical perspective of the disease. By the mid-to-late 1990s, physicians even considered that such new medications had “normalized” the disease — that is, the transformation of HIV into a chronically-managed illness — thus placing it within the catalogue of other once-deadly diseases that had become manageable maladies through techno-scientific intervention.²⁷⁶ Commenting on the emergence of ARTs in the mid-1990s, pediatrician Arye Rubinstein stated that “you’ll be able to keep the AIDS virus at bay for a long time, and slow down the decay of the immune system.”²⁷⁷ Also well-established in the history of the AIDS epidemic is the role activism played in the development of effective ARTs. Gay-male and treatment activists helped change the regulatory structures of drug testing that ultimately led to the discovery and use of effective HIV medications during the last few years of the 1990s.²⁷⁸ Children, of course, would benefit from those medications as well.²⁷⁹

But when considering the treatment of pediatric AIDS, ARTs, though a vitally important breakthrough, came at the end of a broader continuum of health maintenance that started with nursing. By the mid-1980s, healthcare professionals established a multidisciplinary, family-centered standard of care for treating children with AIDS, a

²⁷⁶ For this idea of “normalization,” see: Bayer and Oppenheimer, *AIDS Doctors*, 243. Though Bayer and Oppenheimer do not specifically reference other diseases in this section of the book – aside from briefly mentioning cancer – I am referring to other disease histories that have shown how some deadly illness have become chronically managed disease through the advent of particular techno-scientific interventions. See, for example: John Christopher Feudtner, *Bittersweet : Diabetes, Insulin, and the Transformation of Illness* (Chapel Hill: University of North Carolina Press, 2003); Pemberton, *The Bleeding Disease*.

²⁷⁷ Bayer and Oppenheimer, *AIDS Doctors*, 244.

²⁷⁸ This is particularly informed by the following: Brier, *Infectious Ideas*, 156-189, and; Epstein, *Impure Science*. The history of popular accounts about gay-male activism during the AIDS epidemic – and its impact – is voluminous. My reference to how such activism changed the course of the development of HIV-AIDS medications is meant simply to acknowledge the historical importance of groups like ACT UP and others.

²⁷⁹ Ammann, *Lethal Decisions*.

system built on a chronic-disease model of treatment that preexisted the epidemic.²⁸⁰ By 1988, that system became the gold standard for many healthcare professionals who worked with pediatric-AIDS patients and their families, which persisted through the 1990s. The late 1980s through the mid-1990s, especially, marked a point in the history of pediatric AIDS when the number of cases began to peak; the federal government devoted more resources and attention towards the problem, and a routine healthcare regimen was established as pediatric-AIDS-care professionals gained a firmer grasp of the problem. Nursing, most importantly, was a central component in that system of health care that managed and maintained the health of children with HIV-AIDS, and it was equally important when children and families faced death.²⁸¹

This chapter explores the work of nurses and others who cared for and treated children with HIV-AIDS in and around Newark, New Jersey. There, the Children's Hospital AIDS Program (CHAP) employed a multidisciplinary, family-centered network of care that many healthcare professionals relied on in other parts of the U.S. The CHAP Center — and especially its co-director, Nurse Mary Boland — not only demonstrated how that network of care operated, but it was also one of the central actors in the

²⁸⁰ James Oleske, "Lessons From the Newark, New Jersey Pediatric AIDS Experience," unpublished presentation, [198?] Oleske Personal Papers.

²⁸¹ One of the goals of this chapter is to highlight the work of nurses in developing and implementing the types of pediatric-AIDS care used in the U.S. There is historical literature about the pioneering work of physicians – see in addition to *The AIDS Doctors*, Ronald Bayer and Gerald M. Oppenheimer's "Pioneers in AIDS Care – Reflections on the Epidemic's Early Years," *The New England Journal of Medicine*, 355, no. 22 (November 30, 2006): 2273-2275 – but less has been written about the role nurses played in this respect. Of course, nurses and nursing have been a central component to U.S. health care since at least the middle of the nineteenth century. See, for example: Reverby, *Ordered to Care*; Rosenberg, *The Care of Strangers*; Hine, *Black Women in White*; Fairman, *Critical Care Nursing*; Fairman, *Making Room in the Clinic*; D'Antonio, *American Nursing*. My focus on nursing, here, is less about the centrality of nursing work and professional nurses in health care writ large – though it is most certainly informed and influenced by that historiography – and more about including the work of pediatric AIDS nurses in the historiography of HIV-AIDS. Also, see below for the use of nursing as a category of historical analysis.

establishment of that system of care. By the late 1980s and early 1990s, the CHAP Center housed the National Pediatric HIV Resource Center, and it became the site for an international, philanthropic healthcare organization's efforts to train pediatric-AIDS-care professionals from across the globe. Such institutional recognition was not unique within the larger context of the growing institutionalization of HIV-AIDS research and health care during this time. But CHAP, and its affiliated academic medical center, The University of Medicine and Dentistry of New Jersey (UMDNJ), were not known for cutting-edge biomedical research or health care. Yet the national and international recognition the CHAP Center and its staff received does, however, offer a unique opportunity to understand how and why Newark — a city best known as a symbol of urban decay and late-1960s violent civil unrest — became an important node in the country's efforts to care for children with HIV-AIDS.²⁸²

Through CHAP, I show how a focus on nursing can complicate and supplement our historical understanding about the chronic management of HIV-AIDS. Nurses were well positioned to act as *the* central players in that network of pediatric-AIDS care. This grew out of the nurse's role as maintainer of the patient's health and manager of the complicated systems used in treating those patients. Besides highlighting the work of professional pediatric nurses, nursing provides us a useful category through which to interrogate the relationships, mechanisms, and politics of health care that operate within

²⁸² This is informed by how some historians have begun to complicate the history of Newark that extends beyond analysis of urban decline and of the civil unrest of July of 1967. See, Rabig, *The Fixers* and; Krasovic, *The Newark Frontier*.

and beyond the walls of the clinic during this period.²⁸³ The care of pediatric AIDS patients not only relied on the skills and knowledge of nurses, physicians, and social workers, but it also relied on patients' family members, grandmothers, foster families, and foster care facilities.

Nursing, moreover, provides us a critical vantage point from which to shift our historical perspectives about the introduction of ARTs. Those drugs *saved* lives. But a historical emphasis on the development of those medications transforms effective HIV-AIDS therapeutics into supplanting technologies, rendering everything that came before them as merely “health care in the meantime.” The often-observed work of those that treated and cared for children born with HIV represent an important part of a longer history of HIV maintenance.²⁸⁴

Institutionalizing Pediatric-AIDS Care

Ella was born with HIV-AIDS in 1984. Orphaned at a hospital in Newark, Ella was later cared for by her foster mother. By the time a CHAP social worker began working with her foster mother in 1987, Ella had settled into life with her new foster family. She had four siblings, and according to her social worker, she was cared for by a

²⁸³ Like other categories of analysis – referencing the groundbreaking work of Joan Scott, who argued for using gender as a category of historical analysis – Julie Fairman and Patricia D’Antonio argue that nursing provides a useful tool for historians of medicine that “goes beyond analyzing nursing as a separate entity and as a valid subject and instead insists nursing is relational and instructive to understanding the larger complexities of the politics of health and illness.” See: Julie Fairman and Patricia D’Antonio, “Reimagining Nursing’s Place in the History of Clinical Practice,” *Journal of the History of Medicine and Allied Sciences*, 63 No 4, (October 2008): 435-446; quote derived from 445.

²⁸⁴ This is influenced by a group of scholars called the “Maintainers.” Their work compels us to move beyond stories about “innovation.” Instead, they suggest, we should focus our attention towards those “individuals who keep our world from falling apart...who keep society’s systems running.” See: Andrew Russell and Lee Vinsel, “Let’s Get Excited About Maintenance!” *The New York Times*, July 22, 2017 and Andrew Russell and Lee Vinsel, “Hail the Maintainers,” *Aeon*, accessed April 1, 2020, <https://aeon.co/essays/innovation-is-overvalued-maintenance-often-matters-more>. The quote is derived from the group’s website The Maintainers, accessed April 1, 2020, <http://themaintainers.org/>.

"loving, competent, caring foster parent." Ella's foster mother understood well the physical, medical, and emotional needs of the child. According to the social worker, the foster mother also understood the available support systems, and according to Ella's record, she was well cared for until the child's death in 1989.²⁸⁵

The support systems referenced by Ella's social worker were part of pediatric AIDS care that became routinized and normalized just shortly before the child's death. Ella's short life with HIV-AIDS spanned an important moment in the evolution of pediatric-AIDS health care.²⁸⁶ As seen in chapter two, a number of healthcare institutions in Newark, the Bronx, and Miami emerged as centers for pediatric-AIDS health care and research, in large part because these were the most affected areas of the country. From the late 1980s through the early 1990s, those intuitions, and professionals working within them, drew the attention of federal public health officials and national child-welfare organizations as important representative models for addressing the healthcare needs of children and families with HIV-AIDS.²⁸⁷ The federal recognition of particular models of pediatric-AIDS health care marked a moment in that normalization.

In 1986, the Health Resource Services Administration (HRSA) began awarding healthcare demonstration grants to institutions in cities hard hit by the AIDS epidemic. The demonstration projects were federally-funded efforts to establish models of care for people living with the disease, which included pediatric-AIDS patients and their

²⁸⁵ Patient Record of "Ella," Oleske personal papers (hereafter cited; Ella's Patient Record).

²⁸⁶ Ella's Patient Record.

²⁸⁷ See, for example: Seibert and Olson, *Children, Adolescents & AIDS*; Anderson *Courage to Care*; Antonia C. Novello, Chair, United States Public Health Service Panel on Women AIDS Adolescents, and Children with HIV Infection, *Family-Centered Comprehensive Care for Children with HIV Infection: A Guide* (Washington DC: U.S. Department of Health and Human Services, Public Health Service, 1991); Novello, *Final Report*.

families.²⁸⁸ By 1988, those demonstration projects began to grow. In 1991, HRSA supported twenty-three demonstration projects in the United States, which funded a variety of programs ranging from HIV prevention to health care and social services. The budget for the HRSA-supported programs grew roughly four fold between 1990 and 1991, increasing from \$10 million to \$44 million.²⁸⁹ By that point, HRSA specifically established demonstration programs for identifying model pediatric-AIDS care projects.²⁹⁰

While the demonstration grants funded a number of different organizations, federal health officials saw the family-centered, multidisciplinary approach as the paragon for pediatric-AIDS care. In an Health and Human Services (HHS) report, *Family-centered Comprehensive Care for Children with HIV Infection: A Guide* (1991), the panel responsible for the guide stated: the "survival of many children with HIV infection and AIDS and their families depends on the linkage of existing medical, developmental, and social service systems."²⁹¹ The report highlighted four representative programs that integrated the health care, social services, and developmental modes identified as central to this approach. Of the four, three were linked to hospital-based programs, and one was directly housed within a children's health facility. That program

²⁸⁸ Health and Human Services Administration, "A Comprehensive Analysis of AIDS Service Demonstration Projects in Los Angeles, Miami, New York, and San Francisco," Final Report, October 16, 1989, Box 8, Folder, "AIDS Reports from External Institutions and Governmental Agencies, 1983 – 1992," MC C 544, National Commission Papers.

²⁸⁹ Information about the growth of HRSA support is derived from: Novello, *Final Report* and Novello, *Family-Centered Comprehensive Care*. I derived the budgetary increase in HRSA funds from the latter report, page 17.

²⁹⁰ Novello, *Final Report*, 91–92. See also: *AIDS Service Demonstration Programs : 3 Year Report, 1987-1989*. ([Washington, D.C.?]: U.S. Dept. of Health and Human Services, Public Health Services, Health Resources and Services Administration [sic], 1991); Library of Congress. Congressional Research Service., "Federal Programs Affecting Children and Their Families, 1990" ([S.l.] : [publisher not identified], 1990).

²⁹¹ Novello, *Family-Centered Comprehensive Care*; quote derived from 37; 17.

was the South Texas Children’s AIDS Center located at the University of Texas Health Science Center at San Antonio.²⁹² There, children and families could access a team of medical and social service staff and faculty that addressed the needs of patients in an outpatient or inpatient setting.²⁹³ In short, whether a child required a routine therapy, or needed to see a psychologist, or required a meeting with a social worker, the South Texas team provided all of those services. As Boland explained the CHAP approach — which was similar to other hospital-based programs — such efforts created “a one-stop shop” that helped a family address their health care and social service needs.²⁹⁴

In fact, the South Texas team was representative of the hospital-based approaches that had begun in Newark, the Bronx, and Miami. When the HHS report was published in 1991, those programs were already well-recognized for their pioneering work in establishing a family-centered, multidisciplinary approach. The Child Welfare League of America (CWLA), for example, identified those working in the Bronx and Newark as two model examples. In *Courage to Care* (1990,) the CWLA provided child-welfare and healthcare professionals a collection of examples for what they saw as important approaches to addressing pediatric AIDS. The edited volume not only included hospital-based facilities like those in Miami, the Bronx, and Newark, but foster care facilities and

²⁹² Novello, *Family-Centered Comprehensive Care*, 59-67. The reference to this facility in South Texas demonstrates how the care model first pioneered in Newark, New York City, and Miami – and by the nurses and physicians there – had taken root in other parts of the country. The team in South Texas did, moreover, respond and develop their program, the report mentioned, in reaction to an increase in hemophilia-related HIV-AIDS cases among children, which began in 1985 and peaked in 1988. This also demonstrates how specific regional pediatric AIDS issues helped dictate the development of how certain clinical-care approaches. For example, the HHS report used the South Texas hospital as a representative sample of the clinical-care approach used in many other health care facilities. But the initial focus on children with hemophilia and HIV-AIDS in South Texas differed from the hospital-based programs that emerged as a way to cope with the dual problem of poverty and HIV-AIDS that dislocated families in cities like Newark, New York City, and Miami.

²⁹³ Novello, *Family-Centered Comprehensive Care*, 60-61.

²⁹⁴ Quote derived from Boland oral history.

other community-based organizations that were part of the larger system of pediatric-AIDS care.²⁹⁵

Though there were differences in how each program developed, evolved, and specifically addressed the needs of their patients, the common principle that structured many of these prominent organizations was their emphasis on the continuity of care. The multidisciplinary, continuum-of-care approach was important because of the many social and health problems children faced. HIV-AIDS not only resulted in opportunistic infections: it also hindered the growth and development of children. It was common for children, like Ella, to visit a neurologist, nutritionist, or a developmental psychologist when she arrived at the clinic for her routine check-ups. The child's parent or guardian would or could also meet with social workers to discuss any changes in the home environment, how the child was faring in school, or if there were any issues with child services.²⁹⁶ Most children with HIV-AIDS required the services of multiple healthcare specialists, but poor families were a particular focus for this approach. Nancy Boyd-Franklin, a psychologist that worked with poor families of color, noted that while – the interdisciplinary, family-focused approach was used by many families, “it [was] essential for work with inner-city poor families.”²⁹⁷ The structures of life in a poor, urban community made visiting multiple health specialists and social-service professionals

²⁹⁵ Anderson, *Courage to Care*.

²⁹⁶ Ella's Patient Record.

²⁹⁷ Nancy Boyd-Franklin and Mary G. Boland, “A Multisystems Approach to Service Delivery for HIV/AIDS” in Nancy Boyd-Franklin, Gloria L. Steiner, and Mary Boland, eds., *Children, Families, and HIV/AIDS: Psychosocial and Therapeutic Issues* (New York: Guilford Press, 1995), quote derived from, 200. For Boyd-Franklin's psychological work with black families, see: Nancy Boyd-Franklin, *Black Families in Therapy: Understanding the African American Experience*, 2nd edition, (New York: Guilford Press, 2003).

difficult for some families. Situating many of the needed services in one place was key to ensuring a continuum of care.

Besides monitoring the health of children like Ella, the disruptive nature of poverty *and* a debilitating, deadly disease required persistent social monitoring as well. According to Boland, roughly 50 percent of HIV-AIDS-positive children were orphaned by the disease. If they were not orphaned by the disease, it was common that one or both parents were also coping with AIDS. And for those parents that became too sick to care for a child also meant ensuring someone or someplace took responsibility for the child's health care and other needs. In short, many of the children diagnosed with HIV-AIDS were the responsibility of different people, or different facilities, at different moments in the child's life with the disease. For nurses and social workers, keeping track of those children was, therefore, an important part of the pediatric AIDS-care system.²⁹⁸

By the late-1980s and early 1990s, health care workers across the U.S. also had access to more literature and institutional support from which to draw on when caring for a child and family with HIV-AIDS. In addition to reports published by HHS or publications produced by organizations such as the CWLA, updated epidemiology, science, and healthcare approaches related to pediatric AIDS was captured in large, multi-series texts books like *Pediatric AIDS: The Challenge of HIV Infection in Infants,*

²⁹⁸ Anderson, *Courage to Care* ; Mary G. Boland, Chairperson, and the New Jersey Pediatric AIDS Advisory Committee, *Generations in Jeopardy: Responding to HIV Infection in Children, Women, and Adolescents in New Jersey*, Submitted to Molly Joel Coye, M.D., M.P.H., New Jersey State Commissioner of Health, September 1989, Box 1, Folder 14, NJ AIDS Collection [hereafter cited; *Generations in Jeopardy*].

Children, and Adolescents, first published in 1991.²⁹⁹ Information about pediatric-AIDS-specific care and treatments was also made available through the formation of the HRSA-funded National Pediatric HIV Resource Center (NPHRC). Formed at CHAP between 1988 and 1990, the NPHRC promoted the family-centered, interdisciplinary model; provided healthcare professionals access to information about the treatments for, and management of, pediatric AIDS; offered educational materials and technical support; sought to increase care providers' awareness of, and understanding about, the ethnic and cultural factors that shaped the lives of the people they cared for; and provided space for exploring pediatric AIDS public policy issues.³⁰⁰

At that point, CHAP had become firmly ensconced within the landscape of other healthcare institutions noted for their development of models of care in the United States. CHAP became, moreover, best-known for not only helping develop such models, but they became one of the most recognized Newark-based health care institutions outside of the Newark-New York City metro area. This was due, in large part, because the greater-Newark area experienced some of the highest rates of children born with HIV-AIDS. It was also the result of the work of James Oleske and Mary Boland, two figures who were nationally recognized by other healthcare professionals. In fact, by the late 1980s and early 1990s, Boland, specifically, had already transitioned into her role as director of CHAP and was working to influence pediatric-AIDS policy initiatives at the national and state levels. Along with other nurses, physicians, and scientists, she helped advise the

²⁹⁹ Pizzo and Wilfert, *Pediatric AIDS*, 1991; Philip A. Pizzo and Catherine M. Wilfert, eds., *Pediatric AIDS: The Challenge of HIV Infection in Infants, Children, and Adolescents*, 2nd edition, (Baltimore: Williams & Wilkins, 1994); Pizzo and Wilfert, *Pediatric AIDS*, 1998.

³⁰⁰ National Pediatric HIV Resource Center, Operations Advisory Committee, Information Packet, December 5, 1990, Box 3, Folder 9, NJ AIDS Collection.

HHS working group on pediatric AIDS. She chaired the New Jersey Pediatric AIDS Advisory Committee, and helped in the production of the organizations report *Generations in Jeopardy: Responding to HIV Infection in Children, Women, and Adolescents in New Jersey* [Image 5].³⁰¹ The report and work of the Committee provided an overview of the problem of pediatric AIDS in the state, but also provided recommendations and insight into how healthcare providers and child-welfare professionals might care for children and their families.

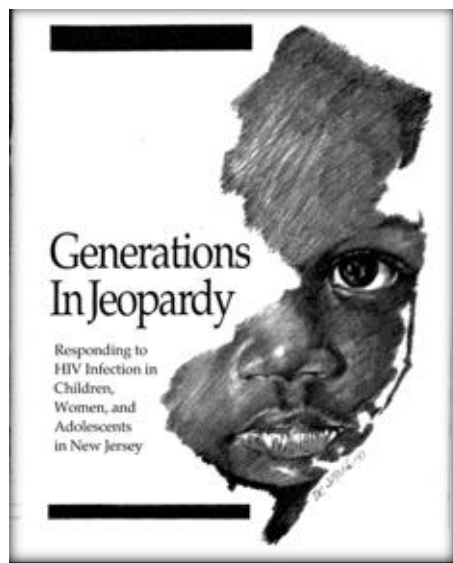


Image 5: Cover, *Generations in Jeopardy* Report

Of course, the development of those models of care were part of a larger ecosystem of pediatric-AIDS-care professionals that not only included physicians and nurses, but social workers as well. In two of the other epicenters of pediatric AIDS —

³⁰¹ *Generations in Jeopardy*. The cover, seen below, of the Committee's report is perhaps unique when compared the vast number of other pediatric AIDS-related reports published during this period. Jamie DeJesus's illustration captures which children were most at jeopardy in New Jersey: children of color. While other reports discussed such disparities, readers of *Generations in Jeopardy* were immediately reminded of, or alerted to, those disparities before even opening the report.

Miami and New York City, specifically the Bronx — two social workers helped maintain and create the systems of care for children at Jackson Memorial Hospital and Albert Einstein College of Medicine. Ana Garcia worked closely with Scott in Miami in the creation and maintenance of the pediatric-AIDS-care program, and Anita Septimus was the coordinator for the Comprehensive Family AIDS Program, where she worked with Rubinstein. Both, along with others in those institutions, were important actors in the establishment of models of pediatric-AIDS care in the U.S.³⁰²

Yet when considering the larger picture of pediatric-AIDS-care centers, CHAP's reputation and national visibility as a premier AIDS-care facility was the result of two important factors: the facility's management structure, and its position in the broader landscape of pediatric-healthcare institutions. Of note was Boland's position as a truly co-equal manager of the CHAP center, which she shared with Oleske. This is not to suggest that the social workers at Jackson Memorial Hospital or Albert Einstein College of Medicine were not important players in their institutions, but the work of Garcia and Septimus was essentially tethered to — and overshadowed by — the reputations of the physicians they worked with and by the intuitions they worked within. Nor did it seem they shared co-equal leadership roles. That was different in Newark: Boland and Oleske helped elevate their institutions exposure in the U.S. According to Nurse Carol Davidson, who was drawn to Newark in the late 1990s because of the work being conducted there, “Mary and Jim were big names in pediatric HIV.” After learning about them by reading

³⁰² See, for example: The New York State Division for Women, *Report of the Public Hearing on AIDS : Its Impact on Women, Children, and Families : Summary of Testimony, Friday, June 12, 1987, 2 World Trade Center, Room 5890, New York, New York* (Albany, N.Y. : The New York State Division for Women, 1987); Seibert and Olson, *Children, Adolescents & AIDS*; Anderson, *Courage to Care*. Some of the information is also derived from, Ana Garcia Interview.

the pediatric-AIDS healthcare literature, she remembered that “they were really impressive trail blazers in pediatric HIV care.”³⁰³

On the one hand, the outsized attention CHAP garnered ran counter to preconceived notions about Newark-area healthcare facilities. Nurse Practitioner Lynn Czarniecki, who worked as a visiting pediatric-AIDS nurse in Newark before joining the CHAP staff in 1988, remembered that the city and state were not well-known for cutting-edge health care. “New Jersey at that time,” she said, “was not a Mecca...of great medical care.”³⁰⁴ Yet one anonymous physician also recognized, and challenged, such perceptions. In a letter to Oleske, the physician — who worked with pediatric-AIDS patients in Newark — wrote: “you have a lot of good research going on despite the mighty snobs who live in germ-free towers of academics who look down on places like...Newark with thinly-veiled disdain and skepticism: ‘can you really do research in that area with that population of patients without an Ivy League University Hospital?’” Such assumptions, he wrote, were “mighty myths” perpetuated by “mighty institutions.”³⁰⁵ As Czarniecki put it, working at CHAP in the late 1980s through the 1990s was “like working in Babies Hospital [New York City]. It was like working at CHOP [Children’s Hospital of Philadelphia]” in Philadelphia.³⁰⁶ While CHAP may have had that reputation, the hospital itself was not as well-resourced as places like CHOP. According to Boland, Children’s Hospital in Newark was “different from a lot of children’s hospitals

³⁰³ Carol Davidson, interview by Jason M. Chernesky, November 27, 2017. Davidson arrived at CHAP in 1998, and she commented on the way Boland and Oleske managed the team: there “was not hierarchy...everyone’s input was [treated] equally.”

³⁰⁴ Lynn Czarniecki oral history, interview by Jason M. Chernesky, August 26, 2018 (hereafter cited; Czarniecki oral history).

³⁰⁵ Letter from [anonymous] to Dr. James Oleske, March 10, 1988, Oleske’s Personal Papers.

³⁰⁶ Czarniecki oral history.

in that it's probably as much a community [hospital]...so they don't have a lot in the way of resources."³⁰⁷

On the other hand, if CHAP's reputation was unique in that context, being designated as a regional AIDS-care center was less prestigious within the larger geography of children's health care institutions. Despite the important work conducted there, few hospitals — and their affiliated academic medical centers — were interested in being a premier AIDS care facility. According to Barbra Kern, who directed New Jersey's Special Child Health Services, "nobody was breaking down the doors to become a designated pediatric AIDS care site." This also reflected the fact that some academic medical centers did not want to be deemed an "AIDS" medical school and research facility.³⁰⁸ Those facilities were, Kern stated, less competitive and prestigious as being designated a prenatal care center, for example. If you were "identified as a regional perinatal center, you get money, your hospital develops prestige," Kern said.³⁰⁹ The politics of biomedical prestige and the economy of institutional funding also helps explain why Newark's children's hospital was best-known for its pediatric-AIDS work: few others wanted the designation of being a pediatric-AIDS *care* facility.

³⁰⁷ Facilitator: Penny Hollander Feldman Case Study Three (Part A) "Children's Hospital AIDS Program: Delivering Comprehensive Services to HIV-Infected Children; quote derived from (Part A) "CHAP and the State of New Jersey: Developing A Statewide Network of Regional Pediatric AIDS Centers," Oleske Personal Papers.

³⁰⁸ Feldman, "Children's Hospital AIDS Program; quote derived from (Part B) "CHAP and the State of New Jersey: Developing A Statewide Network of Regional Pediatric AIDS Centers,"; Oleske also claimed that UMDNJ was not interested in becoming involved with AIDS-related work — a disease, he said, that was not well embraced by the academic medical center, or other institutions, see: Oleske oral history, Rutgers University.

³⁰⁹ Feldman "CHAP and the State of New Jersey: Developing a Statewide Network of Regional Pediatric AIDS Centers"; quote derived from 3.

Although programs like CHAP and others provided the professional staff and expertise needed to care for pediatric-AIDS patients, the vast majority of children were cared for beyond the walls of the hospital. Families like Ella's — along with caretakers from other facilities such as the foster programs that shortly housed children like Ella — were also important actors in a network of health care that also included pediatric-AIDS programs like CHAP. Teams of case managers, assigned to each child and family that were cared for at CHAP, were the connective tissue that held together the network of care. Nurses played a particularly important role in that network.³¹⁰

Nursing and the Network of Care

Like Ella, Andrew was born with HIV. But unlike Ella, he was not orphaned at the hospital. He was cared for by his mother between 1985 and 1990. Then, his mother became labeled as noncompliant by CHAP nurses and social workers shortly before her death from AIDS in 1990. After his mother's death, and after a short stay in a pediatric-AIDS transition facility, Andrew was finally cared for and lived with his grandmother. From 1991 to 1992, the last year of Andrew's life, his CHAP record particularly reveals, through a collection of mundane processes and standard bureaucratic technologies (the "Nursing Progress Note" form), how the different nodes in that network of pediatric-AIDS care operated. Moving between the hospital, home, and foster home, a set of nurses, social workers, child-welfare professionals, and caretakers (like Andrew's grandmother) ensured the proper care for children like Andrew.³¹¹ Specifically, nurses

³¹⁰ Ella's Patient Record

³¹¹ Patient Record of "Andrew," Oleske Personal Papers, (hereafter cited; Andrew's Patient Record).

played an important role as interlocutors between health care professionals, social-services workers, and the child's at-home caretaker.

The care of children at home not only reduced healthcare costs and stress on healthcare systems in resource-poor cities or areas of cities, but the home provided children a better environment in which to cope with the disease. According to one Government Accounting Office report about the health and social service needs of children with HIV-AIDS: “[h]ealth experts agree that, wherever possible, health services for HIV-infected children should be delivered at home to promote maternal bonding and to provide adequate environmental stimulation for child's development.”³¹² Putting that into practice thus relied on coordinated care efforts among the various parties involved.

Nurses were well-positioned to be the linchpin holding together the inpatient and outpatient care components of that system. In 1991, pediatric nurses Janie Eddy, who worked for the NIH, and Sue Whittle, who was the Clinical Trials Coordinator at the University of Maryland, argued that nurses were uniquely positioned, “by virtue of their education and training,” within the multidisciplinary team approach. “Because nurses' understanding of the medical, social, developmental, and psychological aspects of chronic, life threatening illness,” the authors stated, nurses functioned as “the pivotal point in providing, coordinating, and directing the total care of the child with HIV infection and the involved caretakers.” Similar points were made by other nurses during this time. From 1989 to 1995, a number of nurse-educators and scholars familiar with

³¹² General Accounting Office, *Pediatric AIDS : Health and Social Service Needs of Infants and Children : Report to the Chairman, Committee on Finance, U.S. Senate* (Washington, D.C. : The Government Accounting Office, 1989); quote derived from 4.

pediatric-AIDS care, often discussed the central role nurses played — not only in the U.S., but in the United Kingdom as well.³¹³

Of note was the nurse's role in case management. At CHAP and other institutions, case-management teams monitored the health and well-being of children and their families. At CHAP, case-management teams consisted of a nurse and social worker. Working with parents, caretakers, hospital staff, child-welfare workers, and visiting nurses, the team was responsible for coordinating care, assuring that all necessary services were delivered to the child and family throughout the course of the illness, and monitored the health of children.³¹⁴ Only a few teams of case managers were responsible for CHAP patients. In 1990, for example, the CHAP Center had three case-management teams who were each responsible for fifty to sixty families.³¹⁵

One of those teams helped prepare homecare for Gregg and his mother. Gregg's mother was having a difficult time coping with her HIV status and that of her son's. She was willing to "do anything she [could] for Gregg but will not discuss HIV and how it [changed] her life," a case manager wrote in the child's patient record. Despite her

³¹³ See, for example: Mary G. Boland and Richard Conviser, "Nursing Care of the Child," in Jacquelyn Haak Flaskerud and Peter J. Ungvarski, eds., *HIV/AIDS: A Guide to Nursing Care*, 2nd edition, (Philadelphia: Saunders, 1992); Mary G. Boland and Lynn Czarniecki, "Nursing Care of the Child," *HIV/AIDS: A Guide to Nursing Care*, 3rd edition, (Philadelphia: Saunders, 1995); Mary G. Boland and Shelia J. Santacroce, "Nursing Roles in Care of Children and the Family," in Pizzo and Wilfert, *Pediatric AIDS*, 1994; Jacqueline Y. Q. Mok and Marie-Louise Newell, eds., *HIV Infection in Children: A Guide to Practical Management* (Cambridge: Cambridge University Press, 1995) Quote derived from, Janie Eddy and Sue Wittle-Seiden, "Nursing Issues in the Care of HIV-infected Children," in Pizzo and Wilfert, *Pediatric AIDS*, 1991, page 561.

³¹⁴ Information is derived from: Mary G. Boland, "Supporting Families Caring for Children with HIV Infection," 65-77, and Toni Cabat, "The Development of an Early Intervention Model for HIV-Infected Women and Their Infants," 77-91; both are in Anderson, *Courage to Care*. While I do not have the details about how such care systems were administered in the Bronx or Miami – or elsewhere – it is safe to assume that the standards of care used in other places relied on nurses in the capacity that I am discussing here.

³¹⁵ Feldman "CHAP and the State of New Jersey: Developing a Statewide Network of Regional Pediatric AIDS Centers," 7.

emotional and psychological difficulties, and the “somewhat run-down” home, Gregg’s mother carried out the homecare tasks needed to care for the child and herself. According to Gregg’s case managers, his mother was “very competent” in administering medications and the maintenance of particular technologies like Gregg’s boviac catheter (a surgically-installed tube-based port used for administering intravenous medications). Gregg’s mother was also compliant: there is little evidence that she missed many of the regular clinic visits, and she maintained a healthy living environment — despite her health problems and “limited financial resources” — without the assistance of home-healthcare professionals.³¹⁶

Nurses were also well-positioned as healthcare educators because of their knowledge about the biological mechanisms of HIV, nursing’s holistic tradition relative to medicine, and the complicated pediatric-AIDS-care systems families were required to navigate. This was accomplished through conferences with at-home caregivers and manuals developed for families. Nurses and other case managers had a series of educational materials that were written for children as well. The booklet *Jimmy and the Egg Virus* (1988) [Image 6], which was produced and distributed by the NPHRC, educated children about HIV-AIDS, how it could make someone ill, and how it affected the immune system.³¹⁷ Besides educating children about the disease, the booklet provided children and their families a quick snapshot of the healthcare providers that worked inside and outside the clinic — physicians, nurses, and social workers — and how the

³¹⁶ Patient Record of Gregg, Oleske’s Personal Papers (hereafter cited; Gregg’s Patient Record.

³¹⁷ Janie Eddy and Sue Whittle-Seiden, “Nursing Issues in the Care of HIV-Infected Children”; Mary Tasker, MSW, From an original idea by Donatella Graffino, MD, *Jimmy and the Eggs Virus*, Box 1, Folder 7, NJ AIDS Collection. children

staff helped families cope with the disease. Similarly, Dr. Lynn S. Bakers, author of *You and HIV: A Day at a Time* (1991), provided children and their families a more comprehensive guide about the biology of the disease, its management, and what families should expect when treating their child or children.³¹⁸

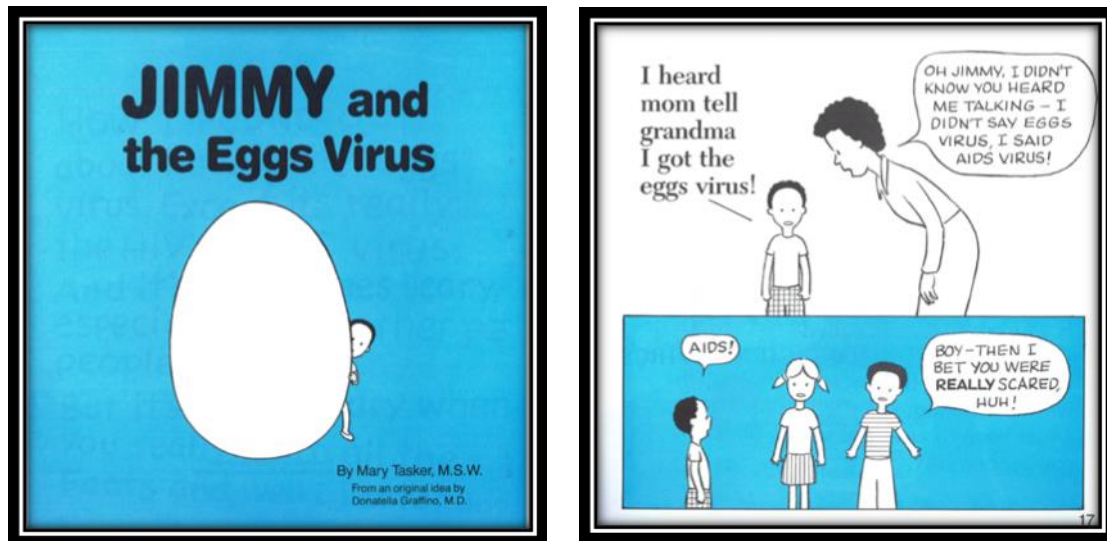


Image 6: *Jimmy and the Eggs Virus*, 1988
Source: NJ AIDS Collection, Rutgers University Medical Library Special Collections

But for those parents who could not care for their children at home, or who had died, foster care facilities for pediatric-AIDS patients provided a space where these children could live, where their continuum of care was not disrupted, and where would-be caregivers learned to administer health care at home. By the late 1980s a number of those facilities, which were often referred to as transition homes, were established in the U.S. There was Grandma's House in Washington, D.C., and the nationally recognized Hale House in Harlem. Clara "Mother" Hale opened and co-ran her facility dedicated to

³¹⁸ Lynn S. Baker, MD, *You and HIV: A Day at a Time*, (W.B. Saunders Company: Philadelphia, 1991).

caring for drug-using women and their children, work that President Reagan praised in a 1985 State of the Union address. In 1987, “Mother” Hale and her daughter Dr. Loraine Hale, opened Hale Cradle, which specifically cared for HIV-AIDS-positive mothers and children. Part of Hale House’s mission was to keep as many children out of the foster care system as possible by keeping families together.³¹⁹

In New Jersey, the AIDS Resource Foundation for Children (ARFC) ran three transition homes throughout the state. Terry and Faye Zealand formed ARFC in 1984, and in 1987 they opened their first of the three transition homes, St. Claire’s, in Elizabeth, NJ. Homes subsequently opened in Jersey City in 1989 and Neptune, NJ, which is outside of Asbury Park, NJ, in 1990. Each home served fewer children than Hale House — parents were also not present at ARFC homes — and provided the social services, health care, and coordination with other agencies to ensure children transitioned to a foster family or extended family member. As, undoubtedly, was the case with such homes, some children may have spent their final days there. By 1993 alone, twenty children had died in ARFC transition homes. According to Terry Zealand, that was “a staggering number given the relatively few families that we served.”³²⁰

Some of the transition homes worked closely with nurses to train would-be caretakers once the child had secured a home. After Andrew’s mother could no longer

³¹⁹ Margolis, *AIDS Children and Child Welfare*; Christopher Laxton, “A Foster Home for HIV Infants: Grandma’s House,” *Caring*, 8, Iss 5, (May 1989): 37-39; “Mother Hale opens home for AIDS children,” *The Baltimore Afro-American*, May 16, 1987. For President Ronald Reagan’s reference to Clara Hale, see: “Hale House to care for babies with AIDS,” *Amsterdam News*, February 22, 1986.

³²⁰ Leslie Berger, “Reaching Out,” *New Jersey Monthly*, March 1989, Box 4, Folder 4, NJ AIDS Collection; Sue Epstein “Haven for Kids with AIDS come to the Shore,” *Star-Ledger*, December 14, 1989; “AIDS Resource Foundation for Children,” Informational flyer, Box 10, Folder 2, NJ AIDS Collection; quote derived from “Orphaned by AIDS—the Outlook,” *AIDS Resource Foundation for Children Newsletter*, Fall 1992, Box 12, Folder 12, NJ AIDS Collection.

care for him, he was sent to St. Claire's through the help of CHAP. From October 1990 to July 1991, he stayed at St. Claire's while awaiting placement, and while the legal custody arrangements were being settled. Besides providing him a stable residence through the transition, the St. Claire staff nurse ensured he received routine check-ups at CHAP and helped train the grandmother for at-home care. In the summer of 1991, Andrew's grandmother made a few trips to St. Claire's where she was given instructions about medication schedules and the use of a nebulizer; she learned how to use syringes for administering medication, and also learned proper safety precautions for treating Andrew, such as appropriate hand washing, the use of gloves, and proper removal of protective equipment and waste materials.³²¹ The facilities were also important for monitoring the relationship between the child and foster parent or between the child and an extended family member. St. Claire's nurse noted that Andrew and his grandmother had a good relationship, and he was acclimating well to the grandmother's home. Towards the end of Andrew's stay at St. Claire's, the nurse visited the grandmother's home where she observed the grandmother's proper use of health care technologies and procedures, and how "Andrew appear[ed] very bonded to [his] grandmother." Andrew was, in fact, quite excited when he learned he was going home with his grandmother, as evidenced by him "constantly repeating 'I stay with Grandma.'" After a going away party, Andrew left St. Claire's on July 16, 1991.

³²¹ Andrew's Patient Record, "AIDS Resource Foundation for Children Progress Notes, June 28, 1991 to July 16, 1991, Oleske Personal Papers.

This example also illustrates how nurses and case managers were an important link between at-home caregivers, foster care facilities, and routine clinic visits. The child's fragile health, coupled with the burdensome lives of poor families, made routine clinic visits a priority in the maintenance of the patient's health. Sometimes this meant routine therapeutic visits. For instance, patients at CHAP and Albert Einstein College of Medicine's AIDS Team regularly received infusions of intravenous gamma globulin (IVGG), which some physicians saw as boosting a child's immune response to opportunistic infections. At CHAP, children visited the hospital roughly once a month to participate in what they called "Friday clinic." Keeping such routines was difficult for families already overburdened by poverty and HIV-AIDS. Routine IVGG infusions were also time consuming, taking hours to complete. Despite those burdens, CHAP reported a 15 percent no-show rate (or an 85 percent compliance rate), which some saw as impressive for an inner-city hospital.³²² It is, however, unclear if other clinics in the U.S. also experienced similar compliance rates.

But the regular clinic visits were most important beyond the patients' receipt of an IVGG infusion. On the one hand, there was little evidence to suggest that IVGG treatments alone helped children fend off opportunistic infections. For parents and caretakers, however, the IVGG infusion provided "social efficacy" instead, or the idea that the very act or ritual of receiving a medical treatment gave them and the patient a sense of solace that they were doing something tangible to control the disease.³²³ Boland

³²² Feldman, "'Children's Hospital AIDS Program'; Boland's oral history.

³²³ The idea of "social efficacy" is derived from the following: Charles Rosenberg, "The Therapeutic Revolution: Medicine, Meaning and Social Change in Nineteenth-Century America," *Perspectives in Biology and Medicine* 20 (1977): 485–506; Charles Rosenberg, *Our Present Complaint: American*

echoed this: the infusions “seemed to the parents like it was “*doing something*” (italics original), which partially might explain the high compliance rates at CHAP. On the other hand, IVGG infusions provided case managers a “captive audience” where they could follow up with parents to see how the child was coping at home, how they were coping in school, or if the child needed to see a specialist while at clinic. The meetings were also an opportunity to meet with the parents and caretakers to ascertain how they were coping, if they were healthy, and if they needed relevant, AIDS-related educational materials. Most importantly, it was at the clinic where healthcare staff cultivated and maintained their vital relationships with the child’s parents or caretakers.³²⁴ Friday clinics were, therefore, an essential part of the interdisciplinary model that stressed a continuity of care. Those meetings were a critical mechanism that not only helped manage the child’s health, but also helped maintain the working relationship between the healthcare staff and the families caring for the children.

Fostering and maintaining those relationships were important because some nurses and other healthcare providers saw the child’s guardian or parent as an important member of the team. For the interdisciplinary, family-centered care network to function, Boland argued “we thought that...the parents or caretakers were also part of that team and we talked about it as a partnership and a collaboration.”³²⁵ Though parents or

Medicine, Then and Now (Baltimore: Johns Hopkins University Press, 2007); Sjaak van der Geest, Susan Reynolds Whyte, and Anita Hardon, “The Anthropology of Pharmaceuticals: A Biographical Approach,” *Annual Review of Anthropology* 25 (1996): 168; Whyte, van der Geest, and Hardon, *Social Lives of Medicines* (Cambridge: Cambridge University Press, 2002), 14-17, 170-1; Robert Aronowitz, “From Skid Row to Main Street: The Bowery Series and the Transformation of Prostate Cancer, 1951-1966,” *Bulletin of the History of Medicine* 88 (2014): 288-9, 312.

³²⁴ Feldman, “Children’s Hospital AIDS Program”; quote derived from page 4. See also: Boland oral history

³²⁵ Boland oral history.

caregivers were drawn into healthcare decision making, some pointed out how the partnership was still managed by hospital personnel. After giving her "spiel" about how caregivers and healthcare providers were partners to a group of parents and grandparents, Boland was asked by one grandmother, "[b]ut who is the senior partner?" Boland acknowledged the grandmother's claim, suggesting that the families depended on the knowledge and expertise of nurses and other health care professionals to ensure they receive the proper training and technologies to care for the children.³²⁶

But there is perhaps an alternative explanation for the grandmother's statement that illuminates the racial and class divide that structured that partnership. It is safe to assume that the grandmother mentioned here — who was likely— poor, working-poor, or at best working-class — was channeling a type of work-related socialization that resulted in questions reflecting an employee-employer relationship familiar to those women. Given that many of the nurses, social workers, and physicians at CHAP were white and educated, the structure of the purposed partnership thus mirrored the racialized hierarchies of employment, not to mention the hierarchies of control in the various systems that many of these grandmothers navigated. In that respect, another way to frame the grandmother's question might be: Who's the boss? In this case, they perhaps saw themselves as working for rather than working with healthcare professionals, most of whom, like other white professionals working in Newark, lived outside the city.

The parents, grandmothers, and foster parents in Newark, as in other poor communities of color, were certainly important partners in the network of pediatric-AIDS care, but that was not new in the age of AIDS. Whether we consider the nationally

³²⁶ Boland oral history

recognized work of “Mother” Hale and her daughter Loraine, or the quotidian labor of Ella’s foster mother and Andrew’s grandmother, such informal healthcare networks have long been part of the Black experience in the United States. In 1991, Dr. Sandra Lewis, a psychologist at the NPHRC, explained to a group of AIDS advocates in Essex County, New Jersey: “this informal caretaking system is an important part of African American culture and needs to be worked with and respected.”³²⁷ Though Lewis did not provide her audience a deeper historical sense of that tradition, her comments nevertheless highlighted how — since at least from the antebellum period through the twentieth century — African-American women, outside traditional healthcare institutions, have provided important care to people in their communities³²⁸ The grandmothers, foster parents, and other family members in Newark, New York City, Miami, and elsewhere were thus participating in a long tradition of caretaking that responded to the healthcare needs of those in their communities affected by the epidemic.

Coping

Although many women were important pediatric-AIDS caregivers, the presence and burden of HIV-AIDS was only one of many problems they had to face. Rebecca was born with HIV in 1988 and was cared for by her mother, who was also living with the disease. CHAP staff recorded how the mother struggled with non-disease related issues. The mother struggled to find family members that wanted to care for her and Rebecca. She struggled to pay her rent, and was evicted from her apartment. For much of Rebecca’s first year of life, her mother desperately tried to care for the child herself, but

³²⁷ Meeting Minutes, May 15, 1991, Essex County AIDS Network, Box 8, Folder 7, NJ AIDS Collection.

³²⁸ See, for example: Susan Lynn Smith, *Sick and Tired of Being Sick*; Fett, *Working Cures*; Nelson, *Body and Soul*.

that was thwarted by her financial circumstances. “I’ve been doing it all on my own for a time,” she told CHAP case managers, “I need the help now.” She received that help, and Rebecca was sent to St. Claire’s while the mother tried to secure stable housing. She never did. She died at the end of 1988. Rebecca lived with a foster family until she died in December 1990 at Children’s Hospital in Newark.³²⁹

The overburdened family was a common phenomenon in many poor urban communities of color in the late 1980s through the 1990s. While HIV-AIDS represented a significant disruption for the lives of gay men and people with hemophilia, the emergence of the disease was yet another issue families of color were forced to cope with. In 1989, historian and civil rights advocate Mary Frances Berry told the *New York Times* that HIV-AIDS in some inner-city communities was "just another plague visited upon people who are already plagued with other problems...[h]ere is another burden added on to those who do not have the resources or the strength to deal with their lives."³³⁰

Such burdens were particularly acute for older women of color, who were not just caring for and raising HIV-AIDS-positive grandchildren. They also usually cared for other grandchildren orphaned because a parent was coping with drug use or they were incarcerated. That was the case for Ms. N, a sixty-four-year-old Puerto Rican grandmother in Paterson, New Jersey. One of her daughters died from AIDS and another was “in and out of jail” because of her drug use. As a result, Ms. N. was the primary caregiver for nine grandchildren, which she cared for in a small, run-down apartment. In

³²⁹ Patient Record of Rebecca [Becky], Oleske’s Personal Papers.

³³⁰ Lena Williams, “Inner City Under Siege.”

addition, Ms. N., like other older women of color, lived on fixed incomes, relied on government assistance, and had chronic health problems of their own (Ms. N. had diabetes).³³¹

How families confronted both HIV-AIDS and a life of poverty varied in degree. The problems experienced by Rebecca's mother and that of grandmothers like Ms. N were typical. In a few extreme examples, some families faced extraordinarily difficult circumstances. Consider Nicholas's family's experience between 1987 and 1992. As an infant, Nicholas and his family were homeless for at least one winter. As his mother's health declined (she also suffered from AIDS) his twenty-year-old sister gained custody of her four siblings, including Nicholas. Within just a few years, the family was evicted from one home, while another home was destroyed by fire. After cashing a welfare check to pay rent, Nicholas's sister was robbed at gun point. She also gave birth to a stillborn child, and became estranged from her boyfriend because of his drug use, which meant that Nicholas's sister lost half the family's income when he left.³³²

Yet the resiliency of families coping with such multiple burdens was something nurses often witnessed and documented. The visiting nurse (V.N.) responsible for Nicholas and his family wrote that while “it appears this young family is more than a little crisis-prone, it is the V.N.’s opinion that there are still strengths, here,” and she recommended the that child protective services work with the older sister, rather than

³³¹ Daphne Joslin, “Introduction” and Carol Mevi-Triano and Elizabeth Paskas, “Caregiving Profiles,” in Daphne Joslin, *Invisible Caregivers: Older Adults Raising Children in the Wake of HIV/AIDS* (New York: Columbia University Press, 2002). Some of the history of mass incarceration in the United States is derived from: Elizabeth Hinton, *From The War on Poverty to the War on Crime: The Making of Mass Incarceration in America* (Cambridge, Mass.: Harvard University Press, 2016).

³³² Patient Record of “Nicholas” Oleske Personal Papers (hereafter cited; Nicholas’s Patient Record).

splitting the family apart.³³³ Nurse Judith Bonyai spoke of the stark juxtaposition between a dismal, "decrepit" housing project building she visited and the "bright" environment of the apartment she found within. The resiliency of the family she visited was memorable because of the "awful circumstances" the family was facing.³³⁴

The problems associated with living in poverty were not the only burdens some families faced. While caring for an HIV-positive wife and daughter, one father, a postal worker in Newark, was mourning the loss of three close family members. In 1994, the man's mother, sister, and niece were murdered. Two years later, the man lost his daughter, Octavia, to AIDS.³³⁵ But in other cases, the burdens associated with raising and caring for a child with HIV-AIDS were far less severe by comparison. Geneva Morrison, a retired, middle-class African American woman lost her daughter to AIDS in 1987. In 1994, she told the *New York Times* that one of the hardest parts of raising her ten-year-old granddaughter Shanti (actual name) was the initial, uncomfortable conversation informing the child that she, too, had AIDS. One night, Shanti brought a children's book about AIDS, which she received from her social worker, to Mrs. Morrison. She asked Shanti, "Do you know what the book is about?" Shanti replied yes. "Do I have AIDS?" the girl asked. "Yes," Mrs. Morris said, "but it's a family secret because people aren't very nice sometimes."³³⁶

But when it came to assisting families struggling with the combined burden of poverty and AIDS, some healthcare professionals were hindered by a lack of resources.

³³³ Nicholas's Patient Record.

³³⁴ Bonyai oral history.

³³⁵ Patient Record of "Octavia," Oleske's Personal Papers (hereafter cited; Octavia's Patient Record).

³³⁶ Felicia R. Lee, "AIDS Toll on Elderly: Dying Grandchildren," *The New York Times*, November 21, 1994. The quotes used here are Mrs. Morrison's direct quotes as they appeared in *The New York Times* article.

In some parts of the U.S., difficulty accessing needed healthcare resources meant that the care network did not always function smoothly. According to Boland and Santacroce, case managers cannot “obtain nonexistent but needed services and are sometimes as powerless as their clients when faced with service gaps.”³³⁷

Nurses also attempted to educate peers about navigating the complicated social relationships with some families, which included personal feelings about a parent’s behavior. In an article for *RN* titled “Starting Life with HIV,” Boland and Czarniecki reminded other nurses that they too had to cope with their feelings, especially towards parents: “nurses sometimes catch themselves blaming the parents for a child’s health problems. Some fantasize about rescuing the children from ‘evil’ parents. Many are distressed by a mother’s decision to have another child.” The latter point, the authors wrote, needed to be understood within the complicated context of how and why HIV-positive mothers, who may have already had one child with the disease, decided to become pregnant again. Mothers may have taken the risk of having another child because there was roughly less than a 50-percent chance of giving birth to an HIV-positive child. The strong urgency to “replace a lost baby,” to give birth to a healthy child, to “leave a legacy” in the face of death, and to satisfy a partner, all factored into a women’s decision to have another child.³³⁸

Although some nurses and social service workers recognized or provided insight about how best to cope with challenges of the job, they too were part of system that was

³³⁷ Mary G. Boland and Shelia J. Santacroce, “Nursing Roles in Care of Children and the Family,” in Pizzo and Wilfert, *Pediatric AIDS*, 1994; quote derived from 804.

³³⁸ Mary G. Boland and Lynn Czarniecki, “Starting Life with HIV,” *RN*, 54, Iss. 1, (January 1991): 54-60; quote derived from 58.

potentially burdensome for families with an HIV-AIDS-positive child or children. Many families of color affected by AIDS were familiar with institutional intrusions into their lives. The health care systems and child-protective services that monitored the health and wellbeing of children with AIDS were just a few such intrusive agencies or institutions — which also include welfare agencies, schools, or law enforcement — families had to manage in their daily lives.³³⁹ That not only meant navigating complicated systems, but it also meant intimate details about their lives were documented and filtered through personal biases. In the summer of 1989, a child-service worker who visited Lauri’s home in the afternoon reported to CHAP staff that the mother was “still in her pajamas and [the] apartment was messy and very dirty and roach-infested.”³⁴⁰

Otherwise mundane coping strategies, often used by adults in stressful circumstances, also came under close scrutiny by case managers or child-services workers. In January 1989, a home health aide informed a CHAP case worker that she became concerned about Ella’s foster mother’s drinking. The aide mentioned that the mother’s alcohol intake had increased, and the same report also mentioned the mother was under significant stress. Though excessive drinking could have posed a problem if it interfered with the care of Ella, there was little evidence to suggest that the foster mother exhibited a pattern of excessive alcohol consumption.³⁴¹

The combination of intruding agencies and a long tradition of mistrusting healthcare systems among African Americans also caused consternation between parents

³³⁹ Nancy Boyd-Fraklin and Mary G. Boland, “A Multisystem Approach to Service Delivery for HIV/AIDS Families.”

³⁴⁰ Patient Record of “Lauri,” Oleske Personal Papers.

³⁴¹ Ella’s Patient Record

and healthcare providers. In January 1996, Octavia's father raised concerns that his daughter was being experimented on after she spent time in the hospital's intensive care unit. The father was also angry at a "DYFS man" — an employee of New Jersey's Division of Youth and Family Services — who had called the father about an incident involving the removal of a nurse from the home.³⁴²

Those families' experiences also stood in stark contrast to how some middle-class children with hemophilia, and their families, experienced life with HIV-AIDS. While issues of class and race led to disparities in the distribution of pediatric AIDS in the U.S., similar social structures factored in how some children experienced life with the disease. In her memoir *Cry Bloody Murder* (1997), Elaine DePrince, who adopted three boys with hemophilia, wrote a moving story detailing how their family coped with the disease. Despite her sons' illnesses, Elaine and her husband ensured their children lived a "normal" childhood in suburban New Jersey. The boys spent summers camping, canoeing, and hiking. And winters were spent ice-skating at the Jersey shore. The DePrinces also purchased a motorhome so that their boys were comfortable during the tedious, one hundred-mile trek to Newark for their routine clinic visits. Two of the DePrince boys died from AIDS.³⁴³

While the burden of HIV-AIDS among some families was complicated by poverty, race, and the specificities of their urban environment, dealing with death was a

³⁴² Octavia's Patient Record

³⁴³ Elaine DePrince, *Cry Bloody Murder: A Tale of Tainted Blood*, 1st edition, (New York: Random House, 1997). I'm not suggesting that families with hemophiliac children that contract AIDS did not experience a number of difficulties. The point here is to illustrate the disparities in those experiences. The example of the DePrince family's experience with AIDS is not meant to exclude other tragic experiences children with hemophilia faced. But the DePrince example reminds us that, among children with the disease, their experiences were in some cases drastically different. Those differences mapped onto the racial and class divides that also separated the DePrinces from many of the families coping with AIDS in Newark.

burden that affected everyone coping with HIV-AIDS. Like adults, children died in their homes and in hospitals. Sometimes they were with loved ones when they died, sometimes they were not. While staying at St. Claire's, Mark's health began to decline in the summer of 1992. He eventually died in the emergency room of Children's Hospital in Newark.³⁴⁴ When Gary's death became imminent in January 1989, his maternal grandparents, his mother, a minister, and friends of the family all came to say goodbye to him. He died at his grandmother's house with his aunt, uncle, and grandmother at his bedside.³⁴⁵ Rebecca, who spent the last two years of her life living with extended family members and in foster care facilities, died in 1990 while receiving hospice care at Children's Hospital in Newark.³⁴⁶

There is some evidence that suggests how children themselves coped with death. At some point in the early 1980s, Oleske was tasked with keeping a boy's prized possession, a stuffed toy rabbit. "I'm dying and I'm going to die," the boy told Oleske, so he gave the bunny to Oleske to ensure his favorite toy would be safe after he was gone.³⁴⁷ Children, of course, feared death as well. In 1987, Michelle accidentally overheard her mother conveying the child's negative prognosis to a sibling. She became "hysterical," and said "I don't want to die." Her records indicate that she subsequently could not be left alone, "even for a few seconds." Michele died at home thirteen days after learning her prognosis.³⁴⁸ Also in 1987, Matthew's psychologist indicated that he "had fears of illness and dying." By 1989 he also became "very angry about his diagnosis" and he had

³⁴⁴ Patient Record of "Mark," Oleske Personal Papers.

³⁴⁵ Gary's Patient Record.

³⁴⁶ Rebecca's Patient Record.

³⁴⁷ For Oleske's response to his dying patient, see: "Dr. Oleske Rabbit," accessed April 1, 2019, https://www.youtube.com/watch?v=C0NvBjSI7_I.

³⁴⁸ Patient Record of "Michele," Oleske Personal Papers.

"questions about why his biological mother used drugs and gave him his infection."³⁴⁹

Though such responses to death mirror how adults may have also reacted to their demise, Czarnieki suggested that children seemed to handle the end better than adults. "Children suffer, adults suffer," Czarnieki claimed, "and in a lot of ways, kids handle it better...kids are much more resilient in that respect than adults."³⁵⁰

Of course, parents and caretakers of children with AIDS not only had to cope with the death of the child, but, as was the case of the biological parents, they also had to cope with a sense of guilt. Some grandparents and foster parents — like Gary's and Ella's — did all they could to reduce suffering and made the child's death as comfortable as possible. Others, like Andrew's grandmother, told a CHAP social worker in the July 1992 that she "wasn't ready for Andrew to die," and seemed to have difficulty coming to grips with the child's death as Andrew's health faded. For some parents, feelings of guilt were common. In the spring of 1994, Mark's mother learned her son was HIV positive. A CHAP counselor noted that the mother became "tearful and stated that she felt guilty [for] giving her child HIV."³⁵¹

Healthcare workers were also profoundly affected by the death of the children they treated. One way of coping with death resulted in collecting memorial ephemera that reminded them of the children. Ana Garcia, in Miami, keeps a "healing tree" in her facility, which is a metal tree that displays the photos of the children that died from the

³⁴⁹ Patient Record of "Matthew" Oleske Personal Papers.

³⁵⁰ Czarnieki Oral History

³⁵¹ Mark's patient record; Nurses and other health care professionals often discussed how mothers coped with guilt. See, for example: Boland and Santacroce, "Nursing Roles in Care of Children and the Family."

epidemic.³⁵² At Oakland's Children's Hospital, the nurses and physicians that treated children there hung reminders of their patients in their hallways.³⁵³ Nurse Czarnieki keeps a framed collage of photos of her ex-patients, and staff at CHAP in Newark planted a memorial garden on the grounds of the hospital, with individual plants representing patients that died.³⁵⁴ The CHAP team also created a scrapbook to remember the patients that died, which was filled with photos of the children, drawings, funeral pamphlets, and a list of those who passed [Images 7 and 8]. It was also common for health care workers to attend the funerals of patients who died.³⁵⁵



Image 7: Drawing from Pediatric-AIDS Patient who Died
Source: CHAP Scrapbook

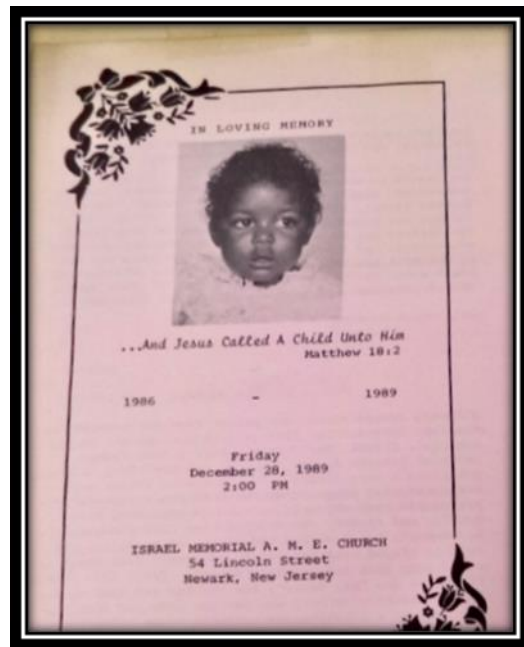


Image 8: Funeral Pamphlet for Three-Year-Old Child
Source: CHAP Scrapbook

³⁵² Garcia Interview.

³⁵³ I witnessed these memorials when I visited Dr. Ann Petru at UCSF Benioff Children's Hospital Oakland, CA in October of 2019.

³⁵⁴ Czarnieki oral history.

³⁵⁵ CHAP scrapbook, Oleske Personal Papers.

Beside memorializing the children, healthcare staff also had to cope with the emotional and psychological consequences of the children's deaths. In a report written by Boland, she explained how the death of eighteen children in 1993 had taken a particularly hard toll on her staff that year. As children began living longer with the disease (nine-to-thirteen years of age), their deaths also became more difficult to bear. "[T]he loss of a child is...especially tragic," the report stated, because "[t]he death is experienced as a more personal manner when you have known the children and family for a period of years." The report continues: "[a]s much as we all strive to be professional, our strength comes from the relationships with families and the perception that we help in some way however small."³⁵⁶

An important mechanism for CHAP staff in coping with emotional fatigue was end-of-week events and weekend retreats that were part of a program called "Helping the Helpers." According to Boland, "Helping the Helpers" was vital for keeping their pediatric-AIDS program together. "I don't think we would have been successful," she stated, "I think we would have imploded." Also, at CHAP, staff managed to cope with the stress of the job and the death of patients through stress-management workshops and group support. Nurse Elaine Gross — who also credited Boland for her efforts in establishing "Helping the Helpers" — stated how staff helped each other the best they could. "If you were having a particularly bad day," she mentioned, "because a child or family that were you particularly close to was dying...[people] stepped up and supported

³⁵⁶ "Annual Report to FXB" 1994, "Helping the Helpers," quote derived from 4, Oleske Personal Papers.

you. There was a tremendous amount of support within the team.” Despite the support, Gross continued, coping with the death of patients “was still hard.”³⁵⁷

The network of pediatric health care that was well established by the late 1980s not only incorporated methods of coping for healthcare workers; it also functioned as a mechanism for families coping with the HIV-AIDS and more. That was evident in the establishment of “Family Place,” an old church across the street from CHAP that the group repurposed as a place to help families with a variety of issues. Family Place provided counseling services, group therapy, substance abuse assessments and referrals, and foster parent training. A group of volunteers also helped families with social and emotional support and domestic work, and provided essential goods like food, blankets, diapers, and clothing. In a letter of support for Ryan White CARE Act funding, one caregiver wrote: “I would surely be unable to [cope] with the normal life of day to day living” if were not for the staff at Family Place. Another mother ended her letter stating: “they showed me that I am still human.”³⁵⁸

Institutions like Family Place, along with its healthcare workers and volunteers, reveals a network of coping that pervaded the experiences of people caring for children with AIDS. From the early 1980s through the late 1990s, families, nurses, social workers, physicians, and hospital staff were drawn closer together through such acts of coping.

³⁵⁷ Elaine Gross, oral history, interview by Jason M. Chernesky, September 22, 2017.

³⁵⁸ Information about Family Place is derived from: The Family Place information pamphlet, “Counseling, Education, Advocacy, and more for HIV-affected Families,” [no date], Box 8, Folder 13, NJ AIDS Collection. Description of Family Place and caregiver testimonials are derived from “Appendix D Community Support, Client/Patient Testimony Letters of Support, Collaborating Agencies,” Dr. Oleske private papers. The letters of support and description of Family Place was part of an application for funding from the Ryan White CARE Act. In a report to FXB funders, CHAP reported that: “[o]ver 200 HIV infected women and their families receive case management, food, housing assistance and social support through the program”: See: “Annual Report to FXB” 1994, 5.

Though certainly not unique to the chronic management of AIDS, this geography of coping nevertheless reveals how, at least in some cities, otherwise socially and physically distant healthcare professionals *had* to intimately confront the various burdens of inner-city life if they were to successfully maintain the health of children.

On the one hand, the function and maintenance of that system of course included the use medical technologies, in the home and in the clinic. On the other hand, the function and maintenance of that system also include access to diapers, food, and a place where families could cope with a scary and deadly disease. While some of those healthcare workers were aware of, and were knowledgeable about, the complicated health problems in poor communities of color, the growth of the pediatric-AIDS-care network during those years made the *other* problems families faced much less distant for those working at places like CHAP. But regardless of how close those problems may have felt to many of the healthcare workers in Newark, they were able to leave them behind when they went home to the suburbs.

The families that remained in the city could not leave those burdens behind. Many of the families that cared for children with HIV-AIDS certainly faced multiple problems that were and were not related to the disease. Some of those families coped well with the disease and other burdens. Others did not. But to simply relegate HIV-AIDS as “just” another burden in a catalogue of many also does not significantly recognize a historical phenomenon that older women of color, in particular, experienced. Perhaps, for the first time since the end of the Second World War, grandmothers, and other older women of color, were coping with and witnessing a disease that eliminated two generations of family members, as well as residents in their neighborhoods and cities. How those many

grandmothers and older foster mothers in Newark coped with that intergenerational loss is, at present, largely unknown.

Exporting the Pediatric-AIDS-Care Model (and AIDS Drugs)

Newark, moreover, provides an interesting coda in our understanding of the pediatric-AIDS-care system in the United States. As a place associated with an important model of pediatric-AIDS care, the CHAP center was part of a larger network of healthcare institutions that helped develop, promote, and practice the family-centered, interdisciplinary system of care. Unlike other healthcare institutions, however, CHAP became an international training center for nurses and physicians treating children with HIV-AIDS in other countries. A Newark hospital might seem like an unlikely site for training healthcare workers from overseas, but the politics of prestige and the economy of pediatric-healthcare funding that made CHAP a regional and national HIV-AIDS center — coupled, of course, with the work of Boland, Oleske, and the other nurses and social workers — also made it an international one as well.

On a rainy night in 1989, a rain-soaked woman arrived at the Oleske's office at CHAP. The woman was the Countess Albina du Boisrouvray, and she had helped create and run an international, philanthropic organization that funded children's health initiatives: the Association Francois-Xavier Bagnoud (or The FXB Foundation). The Countess had traveled to the U.S. to find a location for an international training site for healthcare workers. According to Oleske, she was "rebuffed in New York [City]...no one wanted to talk with her," and after watching the movie *The Littlest Victims* on television while staying in New York City, she traveled to CHAP. In 1990, the FXB Foundation

awarded CHAP \$2.25 million.³⁵⁹ One of the reasons the FXB foundation chose CHAP was due to the work and experience of the team that Boland and Oleske established. Also, unlike better funded and more prestigious research-focused groups like those in Miami and the Bronx, the CHAP center had more to gain — both in terms of funding and recognition — by adopting the training program.

Nevertheless, the FXB Foundation not only funded the creation of an international training center, but also provide support for CHAP workers. Of note was their funding of the “Helping the Helpers” program that Boland argued was vital in the emotional and psychological care of nurses, physicians, and staff.³⁶⁰ But the main focus for the FXB Foundation was the establishment of the International Training Program (ITP), which began training healthcare workers in 1991. Between 1991 and 2000, a host of medical professionals were trained at the FXB Center. Visitors from nineteen countries came to Newark; the nurses, physicians, and other healthcare workers stayed anywhere from one month to a few days (time spent at CHAP was dictated by the types of training they needed).. Each healthcare worker was teamed up with an FXB-CHAP staff person, who had the same professional background as the visitor. For example, physicians would be teamed up with a pediatrician, nurses with a nurse, and social workers with a social worker.³⁶¹

³⁵⁹ Joseph Sullivan, “Newark Visit Yields Millions for youngest AIDS Patients,” *The New York Times*, October 4, 1990. See also: Oleske oral history Rutgers University; quote derived from 19.

³⁶⁰ “Annual Report to FXB, 1994.”

³⁶¹ ““Association: Francois Xavier Bagnoud, International Pediatric HIV Training Program,” 1991[?]. Information also derived from: “Progress Report on FXB activities,” 1991; From Mary Boland to Denis Severis, "Report for Oct 1, 1991 through March 31, 1992," April 28 1992; “Annual Report to FXB, 1994”; "Francois-Xavier Bagnoud International Pediatric HIV Training Program" Three-year Overview,” 1998-2000; Oleske Personal Papers.

The formation of the FXB Center in Newark also came at a time when CHAP staff and others were sent to the then Soviet Union (later the Russian Federation) to help with an outbreak of pediatric AIDS in a small, provincial city called Elista. From 1990 to 1993, CHAP staff and other healthcare professionals helped establish a “mini-CHAP” program in Elista, and they helped monitor the health of the patients during those years.³⁶² Most importantly, the international work of CHAP promoted the family-centered model of care, which included an emphasis on the work of nurses. Reporting on their work in Russia, Dr. Mark Mintz (a CHAP physician) and Boland stated that nurses in the Elista hospital, “previously bystanders [among] direct-care providers, [became] integral members of the health care team.”³⁶³

Boland also made it a point to elevate the status of nurses among their international colleagues, and the presence of a nurse was required for many of the visiting ITP fellows. “I didn’t want nursing to be left out,” Boland claimed. “A physician could come only if they brought a nurse, Boland stated, “it was a way to elevate nursing [into an equal partnership] because this a care system, it’s not a cure system.”³⁶⁴ That persisted through to 2000, by which point many of the healthcare workers traveling to, or receiving instruction from, FXB-CHAP staff became more focused on the administering of ARTs.³⁶⁵

³⁶² Christian M. Hansen, “From Russia with Love: A Report on the Elista Pediatric AIDS Mission,” Oleske private collection; Terry Zealand, “From Newark to Moscow: Pediatric AIDS Delegation,” *Positively Aware*, (summer) 1992, Box 10, Folder 18, New Jersey AIDS Collection; Mark Mintz et al, Notes from the Field, “Pediatric HIV Infection in Elista, Russia: Interventional Strategies,” *American Journal of Public Health*, 85 no. 4, (April 1995): 586-588.; Boland oral history.

³⁶³ M. Mintz et al., “Pediatric HIV Infection in Elista, Russia: Interventional Strategies.”

³⁶⁴ Boland Oral History

³⁶⁵ “Francois-Xavier Bagnoud International Pediatric HIV Training Program” Three-year Overview,” 1998-2000, Oleske Personal Papers.

Of course, by the late 1990s and early 2000s, the use of ARTs became the most important tool for prolonging the lives of children with HIV-AIDS. But administering the medication, like previous health-maintenance techniques, was often done by caregivers at home, and by nurses as well. Guides, such as Czarnieki's coauthored *Family Information Guide*, remained important technologies in the network of pediatric-HIV-AIDS care in the age of ARTs. The guide provided parents and other caretakers with straightforward and useful information ranging from how to administer medications to infants, to how one acquired necessary medications for those who relied on Medicaid.³⁶⁶ The multidisciplinary approach also remained a function of routine pediatric-AIDS care. Writing in 2005, Drs. Elaine Abrams and Lisa-Gaye Robinson, both at Harlem Hospital, stated that nurses, psychiatrists, dentists, social workers, and case managers were still required in the care of children with HIV-AIDS. They noted that through the use of the multidisciplinary approach, coupled with new treatments, children with the disease were living, in some case, into their third decade of life.³⁶⁷

Before the late 1990s, however, there were already signs that children were living longer with HIV-AIDS. Though many of the children had poor prognoses overall — living just a few years after diagnosis — a few studies began to show some improvements in the median survival age. One study, published in the *Lancet* in 1992,

³⁶⁶ *Family Information Guide*, 44-49, Oleske Personal Papers. Information about the authorship of the guide is derived from: Czarnieki oral history.

³⁶⁷ Elaine Abrams, M.D. and Lisa-Gaye Robinson, M.D., "Routine Pediatric Care," Steven L. Zeichner and Jennifer S. Read, eds., *Textbook of Pediatric HIV Care* (Cambridge, UK ; New York, NY: Cambridge University Press, 2005).

showed that roughly 50 percent of the children followed in that study lived to age nine. In 1994, a study in *Pediatrics* showed similar signs of longevity among children born with the disease. In addition, of those followed in that study, about one quarter of the children between nine and sixteen years of age remained asymptomatic. Some pediatric-healthcare professionals suggested that early interventions that prevented pernicious opportunistic infections, and the larger system of chronic-disease maintenance, helped result in the increase life expectancy.³⁶⁸

The increase in survival rates among children with HIV change drastically with the introduction of effective ARTs in the late 1990s. As a new phase in the chronic management of pediatric AIDS began during those years, the staff at the CHAP-FXB Center experienced important changes as well. In February 1997, the healthcare team moved operations to University Hospital, which was attached to UMDNJ in Newark. The hospital group that housed Children’s Hospital and CHAP, United Hospitals, went bankrupt and closed. A headline in the *Star-Ledger* perhaps best captured the closure of Children’s Hospital: “Bloom of Hope Wilts with Hospital Demise.” The article recounted that the closure left behind the memorial garden that patients and staff planted in remembrance of those who died. The patients, staff, and some of the plants were

³⁶⁸ Gwendolyn Scott, et al, “Survival in Children with Perinatally Acquired Human Immunodeficiency Virus Type I Infection,” *The New England Journal of Medicine*, 321, no. 26, (December 28, 1989): 1791-1796; P.A. Tovo et al, “Prognostic Factors and Survival in Children with Perinatal HIV-1 Infection, *The Lancet* 339, (May 23, 1992):1249-1253; Samuel Grubman, et al. “Older Children and Adolescents Living with Perinatally Acquired Human Immunodeficiency Virus Infection,” *Pediatrics* 95 no. 5, “May 1995): 657-663; James Oleske, “The Medical Management of Pediatric AIDS: Intervening on Behalf of Children and Families,” in Anderson, *Courage to Care*.

transferred to their new location at UMDNJ's University Hospital. But not all of the plants made the trip.³⁶⁹

The patients and their families would be cared for in a new location, and the FXB Center continued to operate on the grounds of UMDNJ. But when compared to the other institutions that helped develop pediatric-AIDS care in the U.S., it is safe to assume that the physical space the CHAP-FXB Center occupied was the only one that was abandoned and subsequently bulldozed. The closure of United Hospital was, in many ways, another disruption — a burden, albeit minor by comparison — that patients and practitioners in Newark had to cope with. Those changes were hastened by the politics of healthcare priorities in a city undergoing a “renaissance;” the introduction of new AIDS medications; and, most importantly, the prevention of mother-to-child transmission of HIV.³⁷⁰

³⁶⁹ Gale Scott, “Bloom of Hope Wilts with hospital Demise, *Star-Ledger*, February 22, 1997; Gale Scott, “University Hospital Takes Over United Pediatric,” *Star-Ledger*, February 25, 1997; Steve Strunsky, “Where a Garden Blooms, Children with AIDS are Remembered,” *The New York Times*, August 3, 1997.

³⁷⁰ In a proposal titled “A Proposal for Community Oriented Health Care Services: Division of Allergy, Immunology, and Infectious Disease, January 31, 1997” – which was submitted to the Vice President and CEO of University Hospital, William Vazquez and the Interim Chair, Department of Pediatrics, New Jersey Medical School – Boland and Oleske commented on the course of health care in Newark towards the end of the 1990s. This came just a month before the closing of United Hospitals. It is unclear if the proposal was part of a transition plan, but their comments about partially informing this analysis. They wrote: “The ‘Newark Renaissance’ has passed by too many city residents. Regardless of the lens through which one chooses to view it, health care delivery in Newark fails dismally. Whether we look at health promotion or illness, availability and access to services, or quality of care, Newark lags behind the rest of the state and the country.” See: James Oleske and Mary Boland, “A Proposal for Community Oriented Health Care Services: Division of Allergy, Immunology, and Infectious Disease, January 31, 1997”; quote derived from 2.

CHAPTER 5: THE SPIRIT OF 076: POLITICS AND PRIORITIES IN THE PREVENTION OF PEDIATRIC AIDS, 1985—2001

On February 21, 1994, Tom Brokaw of NBC's *Nightly News* announced the latest "big news in the fight against AIDS." The big news was about a three-year drug trial that studied the use of zidovudine (AZT) in preventing perinatal transmission of HIV to children before and at birth. The trial started in 1991, and three days before the news broke, it was stopped because the study showed a significant reduction in perinatal HIV transmission. Harold Jaffe, an epidemiologist and HIV-AIDS expert at the CDC, told *The New York Times* that the findings were "of major public health importance," and that they showed the "first indication" that the transmission of the HIV to children could be "at least decreased, if not prevented."³⁷¹

The study, AIDS Clinical Trials Group 076, (or simply the 076 trial) was a major turning point in the history of pediatric AIDS in the United States and elsewhere. For the first time since the epidemic began, healthcare professionals and HIV-positive pregnant women were able to drastically reduce perinatal transmission of HIV, if they had access to the medication. Over the next several years, at least in the United States, AZT proved to be the most effective technology in reducing the overall numbers of children born with the disease. For many pediatric-AIDS specialists, the use of AZT was the first significant advancement in their efforts to curb HIV infection among American children.³⁷²

³⁷¹ *NBC Nightly News*, "AZT and Pregnancy," February 21, 1994, VTNA; Lawrence K. Altman, "In Major Finding, Drug Curbs H.I.V. Infection in Newborns," *The New York Times*, February 21, 1994.

³⁷² In his book, Dr. Arthur Amman also expressed an important sentiment held by a number of pediatric AIDS professionals during the late 1980s. Commenting on AZT's use he said it was the "first real step towards" preventing perinatal transmission of HIV. See: Ammann, *Lethal Decisions*, 35. For obvious reasons, the results of the 076 trial provided hope for practitioners and patients alike. The analyses in this chapter are not meant to suggest the important preventative efficacy and value of AZT. Instead, I attempt to

But the use of AZT, though mostly successful, was not the only prevention strategy used in reducing perinatal transmission of HIV. This final chapter follows the significant prevention efforts Americans deployed before, during, and after the 076 trial. From 1985 to 1994, prevention efforts largely targeted women, especially women of color. As Congressman Ted Weiss (D-NY) put it in 1987: “women in high risk groups should be a special target of prevention strategies, for most pediatric AIDS is acquired perinatally.”³⁷³ As we will see, efforts to prevent pediatric AIDS urged women to avoid HIV infection, or if HIV-positive, to avoid becoming pregnant. From 1985 through the 1990s, therefore, getting women tested for, and counseled about, the disease was a primary focus for public-health professionals, policy-makers, and healthcare providers.

Prevention efforts that targeted women, in turn, helped give rise to women’s-health advocacy efforts that empowered women to make their own choices about HIV prevention and reproduction. Some of those advocates were nurses and physicians, others were grassroots organizations that grew out of places with high incidences of HIV-AIDS among women of color — namely New York City and New Jersey. Like many pediatric-AIDS-prevention advocates during this time, women’s-health advocates recognized that one of the most effective means of preventing HIV in children was to prevent HIV infection in women. Most importantly, they also became a critical voice for ensuring that women were equally recognized in HIV prevention efforts. As one women’s-health advocate stated in 1990, HIV-AIDS in women “only became an issue when it was

show a more complicated picture of pediatric AIDS prevention that did not solely include the development and use of AZT. Also, I am using AZT, rather than ZDV throughout the chapter. Technically, the shorthand for the pharmaceutical used in reducing perinatal transmission of HIV is ZDV, but for purposes of consistency, I am using AZT. In addition, many of my actors primarily used the shorthand AZT during the years covered in the chapter.

³⁷³ *A Generation in Jeopardy Children and AIDS*, 136.

established that HIV infection was being transmitted from mother to newborn.”³⁷⁴

Because the prevention of perinatally acquired HIV centered on preventing HIV in women, or educating HIV-positive women about their childbirth options, women’s-health advocates thus became an important part of the broader landscape of pediatric-AIDS prevention in the U.S. during the 1990s.

Equally important in considering the larger picture of pediatric-AIDS prevention were the efforts of harm-reduction specialists that worked to prevent HIV transmission among IV drug users.³⁷⁵ If perinatally acquired HIV was inextricably linked to the mother’s HIV status, it was also closely linked to the prevalence and patterns of IV drug use in some American cities. Through educational initiatives, drug users were encouraged to practice safe sex, not share syringes, and to use sterile needles — or to disinfect them — so as to reduce the chance of transmitting HIV to their sexual partners and children. In fact, an effort to reduce HIV among drug users *and* their children was a central theme that permeated prevention literature and conversations about harm-reduction strategies. From the early 1980s through the 1990s, harm-reduction specialists understood that HIV-AIDS was a “family disease among intravenous drug users.”³⁷⁶ In that context, harm-reduction specialists explicitly argued that the distribution of sterile

³⁷⁴ *Focus*, The Essex County AIDS Network Newsletter, Vol 1, No 1, March – April 1990, “Women: Invisible, Silent, and Dying,” The quote is derived from Diana Palladino (quoted in the article) who was a founding member of the New Jersey Women’s AIDS Network – a group I will discuss later in the chapter. The newsletter was part of the New Jersey Women’s AIDS Network 2nd Annual Symposium “Confronting the Crisis: the Power of Our Voices, September 17, 1990, Box 3, Folder 12, NJ AIDS Collection.

³⁷⁵ I am using harm-reduction in this chapter as a shorthand for people and professionals that worked to reduce HIV infection among IV drug users. That included everything from disseminating prevention literature to the distribution of sterile syringes – or the attempts to distribute clean needles.

³⁷⁶ Don C. Des Jarlais, Samuel R. Friedman, and Thomas P Ward, “Harm Reduction: A Public Health Response to the AIDS Epidemic Among Injecting Drug Users,” *Annual Review of Public Health*, 14, no. 1 (1993): 413-450.

syringes would effectively curb HIV infection among families, but such claims were not universally accepted, even in states and cities with high numbers of HIV among men, women, and their children.³⁷⁷

Though AZT became the dominant and most effective means of preventing pediatric AIDS after 1994, we cannot fully understand the prevention of perinatally transmitted HIV without considering the work of women's-health advocates and harm-reduction specialists. Besides helping prevent HIV in women, and helping HIV-positive women navigate complicated choices surrounding pregnancy, women's-health advocates also helped inform CDC protocols designed for the use of AZT in pregnant women. They also became supporters of clean-needle distribution programs in the 1990s. When discussed alongside the efforts of harm-reduction specialists, we see how their interventions, unlike few others, provided the most holistic approach that sought to mitigate the effects of the ecologies of injustice that resulted in HIV infection among *families* of color (see chapter one). But those efforts were not a national priority supported by the full weight of the federal government. Moreover, public health scientists understood the various complexities related to pediatric-AIDS prevention in some American cities and called for targeted approaches. "We acknowledge," a public health scientist wrote in 1987, "that the social and economic reality for women of childbearing

³⁷⁷ Scholars have addressed the contentious political debates about providing IV drug users with sterile syringes, but they have not interrogated how those harm-reduction strategies were specifically framed as perverting AIDS in children and their families. See: Warwick Anderson, "The New York Needle Trial: The Politics of Public Health in the Age of AIDS," *American Journal of Public Health*, 81, no. 11, (November 1991): 1506-1517; Colgrove, *Epidemic City*, 162-170; Baldwin, *Disease and Democracy*, 142-152; Gostin, *The AIDS Pandemic Complacency, Injustice, and Unfulfilled Expectations*, 251-275.

age in our inner cities cannot easily be changed; therefore, we must consider...more limited...strategies of disease prevention and control.”³⁷⁸

This is important in understanding the development and use of AZT. The impulse to find technological solution for biomedical problems is not new to the history of pediatric AIDS. Moreover, as we will see, the drug’s use after 1994 was the central tool for nearly eliminating pediatric AIDS in the country. The drug’s success was also due, in large part, to the work of nurses and social workers. But the rise and use of AZT must be understood within the context of the burdens of prevention, which were exacerbated by the complicated social and environmental problems that structured the problem of AIDS among families of color. In that context, the development and success of AZT in preventing perinatal transmission of HIV was a *specific* techno-scientific response to the nation’s broader failures to adequately address HIV-AIDS in poor urban environments.

Preventing Pediatric AIDS Before AZT

Beginning in 1985, efforts to prevent perinatal transmission of HIV essentially relied on two dominant strategies. That year, the CDC published its first pediatric-AIDS prevention guidelines, which centered around testing and counseling women who were at “increased risk” of acquiring the disease. The CDC also recommended that healthcare and public-health workers educate uninfected women as to how they could avoid contracting HIV-AIDS. For HIV-positive women, the CDC urged counseling so that women could “choose to delay pregnancy until more is known about perinatal

³⁷⁸ Michael T. Osterholm and Kristine L. MacDonald, “Facing the Complex Issues of Pediatric AIDS: A Public Health Perspective,” *JAMA* 258, no. 19 (November 20, 1987): 2736–37.

transmission of the virus.” Aiding in those efforts was the relatively new anti-body test.³⁷⁹ From the mid-1980s and beyond, testing became one of the more important tools for the prevention of perinatally acquired HIV.

By 1986 and 1987, the testing-and-counseling method of prevention was disseminated through public information campaigns. In Surgeon General Koop’s widely circulated 1986 pamphlet about AIDS, he recommended that women “think carefully” before becoming pregnant, especially if they were in a “high risk” group. He spelled out, in plain language, who was at greatest risk: IV drug users, women that had sex with bisexual men, or who had sex with a man that was an IV drug user.³⁸⁰ That same year, James Oleske and Gwendolyn Scott wrote an AIDS-educational pamphlet for ZOE International Inc title “The Facts about AIDS.” In it, they instructed women of child-bearing age to know their HIV-AIDS status as to avoid “jeopardizing” their health and the health of their unborn children. Most importantly, they recommended a woman should “delay pregnancy until she had determined whether or not she is carrying the AIDS virus.”³⁸¹ By 1987, the CDC and local health departments also emphasized the pre-pregnancy testing and counseling in a nationwide AIDS-education campaign, “America Responds to AIDS.” Besides producing posters that urged women to know their HIV-AIDS status [Images 9 and 10], the CDC also recommended testing and counseling in

³⁷⁹ CDC “Recommendations for Assisting in the Prevention of Perinatal Transmission of Human T-Lymphotropic Virus Type III/Lymphadenopathy-Associated Virus and Acquired Immunodeficiency Syndrome,” *MMWR* 34, no. 48 (December 6, 1985): 721–26, 731–32.

³⁸⁰ C. Everette Koop, Surgeon General of the United States, *Surgeon General’s Report on Acquired Immunodeficiency Syndrome*, Health and Human Services, October 22, 1986, Box 1, Folder 11, NJ AIDS Collection.

³⁸¹ Dr. James Oleske and Dr. Gwendolyn Scott, “The Facts about AIDS,” ZOE International Inc, Folder 1, Box 273, Baruch S. Blumberg Papers, American Philosophical Society, Philadelphia, PA.

published literature, such as their *AIDS Prevention Guide: The Facts about HIV Infection And AIDS*.³⁸²



Image 9: CDC AIDS Prevention Poster from "America Responds to AIDS," 198[?]
Source: National Library of Medicine Digital Collection

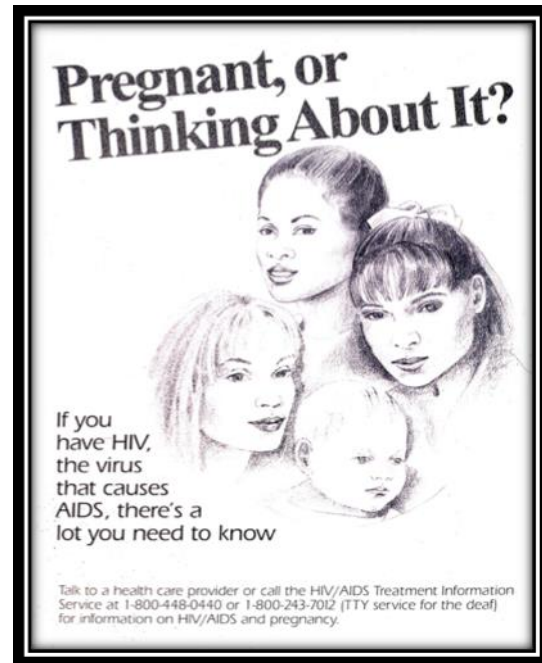


Image 10: HIV-AIDS Information Poster for Pregnant Women from Treatment Information Service [No Date]
Source: National Library of Medicine Digital Collection

In addition to encouraging women to be tested for, and counseled about HIV-AIDS, public-health and healthcare professionals argued that preventing HIV among women was one of the surest ways to prevent the disease in children. In 1987, at the Surgeon General's Workshop on Children with HIV Infection and Their Families,

³⁸² AIDS Prevention Guide: The Facts About HIV Infection and AIDS, Box 10, Folder 12, NJ AIDS collection. Information about the CDC's work is derived from: "America Responds to AIDS, updated July 29, 2016, accessed January 1, 2019, <https://www.nlm.nih.gov/exhibition/survivingandthriving/digitalgallery/america-responds-to-AIDS.html>. See: "Pregnant, or Thinking about it?" The Treatment Information Service, 19[?], accessed January 1, 2019, <https://collections.nlm.nih.gov/catalog/nlm:nlmuid-101455464-img>; "I didn't know I had AIDS – not until my baby was born with the It," U.S. Centers for Disease Control, [198-], accessed January 1, 2019, <https://collections.nlm.nih.gov/catalog/nlm:nlmuid-101444900-img>. Both of the posters are found at: U.S. National Library of Medicine, Digital Collections (hereafter cited; NLM Digital Collection).

Gwendolyn Scott stated that “[p]revention of perinatal infection will only be accomplished by prevention of disease in women or by other interventions, such as drug therapy.”³⁸³ From at least 1986, women’s-health organizations, nurses, public-health workers, and physicians promoted educational efforts to help reduce HIV transmission among women through “risk-reduction,” such as practicing safe sex and safe IV-drug-using techniques.³⁸⁴ In 1989, writing in the journal *Pediatrics*, nurses and physicians at the NIH’s Pediatric Branch argued that it was “critical” that women were educated about not sharing syringes and that they should not have unprotected sex with partners that were at high risk of contracting HIV.³⁸⁵

Given those concerns, we see how public-health educational materials commonly informed IV drug users about the links between IV drug use, HIV-AIDS, and children. From the late 1980s and into the 1990s, public health educational campaigns, at the local and national levels, specifically communicated to women to stop using drugs for the sake of their unborn child. [Images 11 and 12].³⁸⁶ But such messages did not solely target

³⁸³ Gwendolyn Scott, “Natural History of HIV infection in Children,” in *Report of the Surgeon General’s Workshop on Children with HIV Infection and Their Families AIDS*; quote derived from 23.

³⁸⁴ In 1987, the San Francisco AIDS Foundation compiled guide of related and up-to-date public health and scientific information related to HIV-AIDS in women. The articles, and the guide itself, represent some of the efforts women’s-health workers engaged in during these years. For example, George Rutherford et al, “Guidelines for the Control of Perinatally Transmitted Human Immunodeficiency Virus Infection and Care of Infected Mothers, Infants and Children,” City and County of San Francisco Department of Public Health Perinatal and Pediatric AIDS Advisory Committee, *The Western Journal of Medicine*, 147 (July 1987): 104-108; Barbara G. Faltz, RNC, BSN and Scott Madover, MFCC, “Substance Abuse as a co-factor for AIDS,” AIDS Substance Abuse Program, UCSF Health Project,” both in Women’s Program of the San Francisco AIDS Foundation, *Women and AIDS Clinical Resource Guide*, 2nd edition, (San Francisco: San Francisco AIDS Foundation, 1987).

³⁸⁵ Judith Fallon et al, “Human Immunodeficiency Virus Infection in Children,” *The Journal of Pediatrics* 114, no. 1 (January 1, 1989): 1–30.

³⁸⁶ The creator of the flyer from the San Francisco area is unknown; “HIV-prevention flyer,” Box 129, Folder “IV [intravenous] Drug Abuse,” Shilts Papers; “Most Babies with AIDS are born to mothers or fathers who have shot drugs,” National Institute of Drug Abuse [198-], NLM Digital Collection, accessed January 1, 2019, <https://collections.nlm.nih.gov/catalog/nlm:nlmuid-101438823-img>. See also: “I.V. drug user: don’t give AIDS to your unborn baby,” 1986, Georgia Department of Human Resources, NLM

women. Because women also contracted HIV heterosexually, many educational materials were geared towards both men and women. In New York City, the Department of Health produced a poster titled “AIDS, Sex, and Drugs: Don’t Pass it On,” which displayed an illustration of a man and woman embracing inside a syringe. Emerging from the tip of the needle is a drop of red blood, which contained an image of a fully-formed fetus.³⁸⁷ Most common were educational materials such as *The Works: Drugs, Sex, & AIDS* (1987), a comic-style information guide for drug users produced by the San Francisco AIDS Foundation, and “Dying to Get High – AIDS and Shooting Drugs,” which was distributed by the New Jersey Department of Health. In both examples, men and women learned that unsafe drug-using practices and unprotected sex led to HIV infection among themselves, their sex partners, and their unborn children.³⁸⁸

Digital Collection, accessed January 1, 2019, <https://collections.nlm.nih.gov/catalog/nlm:nlmuid-101438758-img>; “This I.V. drug addict has AIDS,” Texas Department of MHRM, AIDS Prevention Project, 1987, NLM Digital Collections, accessed January 1, 2019, <https://collections.nlm.nih.gov/catalog/nlm:nlmuid-101447802-img>.

³⁸⁷ “AIDS, sex and drugs: don’t pass it on!” 198?, New York Department of Health, NLM Digital Collections, accessed January 1, 2019, <https://collections.nlm.nih.gov/catalog/nlm:nlmuid-101438771-img>; “Pediatric AIDS: Background and Progress,” *Public Health Reports* 103, Supp. No 1 (November 1988): 94-97.

³⁸⁸ San Francisco AIDS Foundation, *The Works: Drugs, Sex & AIDS*, 1987, Box 129, Folder “IV [intravenous] Drug Abuse, Shilts Papers; “Dying to Get High – AIDS and shooting drugs,” Box 8, Folder 10, NJ AIDS Collection.



Image 11: HIV-Prevention Poster for IV Drug Users, San Francisco [No Date]
 Source: Randy Shilts Papers (GLC 43) James C. Hormel LGBTQIA Center, San Francisco Public Library



Image 12: HIV-AIDS Awareness Poster, National Institute on Drug Abuse, [198?]
 Source: National Library of Medicine Digital Collection

Meanwhile, beginning around 1985, one of the leading experts on HIV-AIDS among IV drug users, Don C. Des Jarlais, argued that providing free sterile syringes to users would help reduce HIV transmission among users, heterosexual partners, and children. Des Jarlais, a social scientist by training, was an expert on IV drug use and users before the epidemic began. Researching IV drug users when the epidemic unfolded, he quickly became an expert in studying HIV-AIDS among drug users, especially in New York City. By the mid-1980s, he was also the Assistant Deputy Director for Research Evaluation at New York State’s Division of Substance Abuse. In a letter to the editor of *The New England Journal of Medicine*, he stated that in absence of an effective treatment or vaccine, uncontaminated syringes could help control the spread of the virus. In the United States, he wrote, “intravenous drug users are the primary source of transmission to

heterosexuals and to children.”³⁸⁹ In addition to recognizing the importance of educating IV drug users about HIV-AIDS, proponents of distributing sterile syringes saw such a seemingly minor intervention as having significant potential in reducing HIV among users and their families.

One of the earliest and most politically contentious attempts in establishing a clean-needle distribution program occurred in New York City, and the justification for that initiative focused on the nexus of IV drug use and children born with AIDS. In the summer of 1985, the New York City Commissioner of Health, David Sencer, wrote to Mayor Edward Koch asking him to reevaluate the legal obstacles to obtaining clean needles. “I believe it is time to reevaluate...[our] society’s approach to drug abuse,” Sencer argued, because by “forcing addicts” to share syringes, they were essentially condemning them to “Death from AIDS.” Most important, he added, an “addict infected with [HIV]...continues the spread of AIDS not only to other addicts, but to their sex partners, and tragically to children born of such parents.”³⁹⁰

Legal questions loomed large in public-health conversations and initiatives that targeted IV drug users, and not just when the distribution of clean-needles was proposed. In New Jersey, the state’s first AIDS taskforce noted the potential legal issues in educating IV drug users about how to safely use drugs. At a meeting in April 1984, the committee was concerned about being seen as “condoning an illegal activity,” to which

³⁸⁹ Don C. Des Jarlais, and William Hopkins, “Free Needles for Intravenous Drug users at Risk for AIDS: Current Developments in New York City,” *The New England Journal of Medicine*, 313, no. 23 (1985): 1476. The biographical information is provided by Don C. Des Jarlais’ CV – Des Jarlais provided me the CV. His biography, and role working in New York City, is also derived from: Colgrove, *Epidemic City*, 163. In addition, according to Colgrove, clean-needle distribution advocates and public health scientists were informed by needle-exchange programs in European countries that were in effect by 1984.

³⁹⁰ David Sencer to Mayor Edward Koch, “Reuse of Needles and Syringes,” August 13, 1985, Box 168, Folder 9, Mayor Edward Koch Papers, New York City Municipal Archives.

Assemblywoman Angela Perun (a member of the taskforce) bluntly stated: “Addicts will shoot drugs regardless of our advice,” she said, “it is our moral duty to inform them of how to make that activity safer.”³⁹¹ But the distribution of harm-reduction literature (whether a poster or pamphlet) did not become controversial: programs designed to distribute sterile syringes to drug users did. By 1986, when information about the proposed needle-exchange program in New York City was purposefully leaked to the public, it met stiff opposition from political and community leaders in the city. For public-health officials in the city, the most politically efficacious path forward was to first establish a pilot needle-exchange study, which was meant to show the public-health efficacy of distributing sterile syringes.³⁹²

What emerged from the New York City’s attempt to establish a needle-exchange program in the late 1980s, most importantly, was the ways in which health officials reminded the public that clean needles could help reduce HIV among women, and especially children. That was, in part, a political strategy to make such initiatives more palatable. In his effort to kickstart the syringe-exchange program in New York City, the new Commissioner of Health, Stephen Joseph, lobbied the state’s Department of Health for support. Writing to the state’s Commissioner of Health, David Axelrod, Joseph stated that, ““I know that you share my sense of the urgency of exploring all feasible ways to

³⁹¹ New Jersey Commissioner of Health’s Advisory Committee on the Acquired Immune Deficiency Syndrome (AIDS), AIDS Tacks Force Minutes from April 16, 1984, Oleske Personal Papers.

³⁹² Colgrove, *Epidemic City*, 163-164.

slow transmission of HIV in the IVDA population, and from them to women and infants.”³⁹³

Calls to help save the “innocent victims” of HIV were not new in 1987, but some saw those tactics as particularly useful for drawing attention to a population of Americans few wanted to help: IV drug users. At a conference that focused on AIDS among IV drug users, A.R. Moss, a public-health scholar from the University of California, San Francisco, argued in his paper that “there are some particular aspects of AIDS in IV drug users that are useful to bring to the attention of policy makers and legislators who are asking the question, Why prevent it? Or at least asking the closely related questions, Why pay a lot of money to prevent it?” Moss was speaking specifically about harm-reduction among IV drug users writ large, but he added that it was important to remind legislators and policymakers that “IV drug use is also responsible for half of the children with AIDS. This is the largest single category, and it's going to increase.”³⁹⁴ In 1987, healthcare professionals took a similar approach during the hearings for Presidential Reagan’s Commission on the AIDS epidemic. In fact, at a “Intravenous Drug Abuse and HIV Infection” hearing, a significant portion of the testimony discussed how children, and women, were affected by the nexus of IV drug use and HIV transmission.³⁹⁵

³⁹³ Letter from Stephen Joseph to David Axelrod, April 19, 1987, Box 89, Folder “Needle Exchange, Stephen Joseph response to Officials,” NYC DOH Commissioner Files.

³⁹⁴ Transcript of Proceedings the conference, Center for Health Facilities Research and New Jersey Department of Health, “AIDS in Drug Abuse Community and Heterosexual Transmission,” The Newark Airport Marriott Hotel, Newark, NJ, March 31, 1986, A.R. Moss’ paper, “AIDS in IV Drug Users,” is found in the “Workshop C” section of the proceedings, Box 1, Folder 12, Department of Health Commissioner Subject Files, 1973 – 1990, New Jersey State Archives.

³⁹⁵ Hearing on IV Drug Abuse and HIV, December and 18, 1987, National Commission on Acquired Immune Deficiency Syndrome, Box 1, Folder “IV Drug Abuse and HIV Hearing,” National Commission Papers.

Through much of 1988, as the pilot needle-exchange began, references to “saving” women and children were not merely part of a larger political strategy to convince the public to accept the distribution of clean needles in the city. In communicating their motives for establishing a needle-exchange program, health officials saw those harm-reduction strategies as one of many *essential* tools in preventing HIV among women and their children. The connections between pediatric AIDS and IV drug use was, after all, an epidemiological fact, something that health officials underscored. That year, for example, Stephen Joseph responded to high school students in Queens who opposed the proposed needle-exchange program in New York City. At the beginning of his response to the students, he mentioned, as he had done before, that “almost 80% of all new pediatric are related to intravenous drug use by the mother or father or both.” He went on to remind them that needle-exchange policies would not encourage drug use, and that such efforts were part of a broader initiative to help drug users change their behavior, which put “them and their sexual partners and infants at risk for AIDS.”³⁹⁶

Joseph also used those facts as a moral cudgel against those who he saw as propagating short-sighted and potentially dangerous views about distributing clean needles. Writing to Michael Pakenham, the Editorial Page Editor at the *Daily News*, Joseph objected to an article titled “Halt Needle Madness before it Kills.” He specifically objected to the story’s characterization of IV drug users as “insane zombies,” that were “overwhelmingly incapable of human discretion.” He asked: “Does the News mean to say that we should neither try by all possible means to prevent AIDS in IVUDUs, nor prevent

³⁹⁶ Letter from Stephen Joseph to Mrs. Smith-Campbell, John Bowne High School, October 26, 1988, Box 89, Folder, “Needle Exchange, Stephen Joseph Response to Citizens,” NYC DOH Commissioner Files.

the onward infection of their spouses, sexual partners, and unborn children? From both [a] public health and [a]moral standpoint, I sincerely hope not” (underlining was original).³⁹⁷

In the end, clarion calls to protect women and children from HIV did not save the pilot program in New York. It foundered for a few years, and the study ended in 1990. Two years later, Margret Hamburg, the city’s new Health Commissioner, skillfully used compressive scientific evidence — not the threat of infected women and children — to convince Mayor David Dinkins to adopt needle-exchange programs in the New York.³⁹⁸ But beyond New York City, conversations about implementing needle exchange programs as part of larger harm-reduction strategies to protect women *and* children would continue over the next several years. And by the early 1990s, clean-needle advocates would further emphasize how sterile syringes would protect *families* from HIV.

As New York City was embroiled in controversy about distributing clean needles to drug users, women’s-health advocates and activists began raising awareness about the lack of attention paid towards the problem of HIV-AIDS in women. In 1987, for instance, women at the Third International Conference on AIDS questioned why there were only 19 out of 370 speakers who discussed public-health and healthcare issues related to AIDS in women. More importantly, women’s-health advocates and activists were becoming increasingly critical about the ways in which the medical and public-health communities

³⁹⁷ Stephen Joseph to Michael Pakenham, Editorial Page Editor, *Daily News*, October 13, 1988; see also Stephen Joseph to John D. Sicher, Editor, *The New York Observer*, November 19, 1988, Box 89, Folder, “Stephen Joseph Response to the Media” Oct 1988 article to Daily News; NYC DOH Commissioner Files.

³⁹⁸ Colgrove, *Epidemic City*, 169 – 170.

treated women (especially in HIV prevention campaigns) as vectors of disease for men and their unborn children. Dr. Constance Wofsy , who attended the conference, told a reporter that she felt little attention was being paid to the complicated choices women with HIV-AIDS had to make, such as issues related to reproduction. Moreover, she felt the overall lack of attention towards women’s issues relating to HIV-AIDS did not address “women as the human beings they are.”³⁹⁹

Over the next several years, women’s-health advocates would emerge as important actors in debates about HIV prevention in women and children. They not only sought to mitigate the harmful effects of IV drug use and HIV, which disproportionately affected poor women of color, but they voiced important challenges about the way women were represented in prevention campaigns and policy initiatives. One of the central missions among many women’s-health advocates centered around empowering women to make educated choices about complicated issues related to HIV and reproduction.

“What About the Mothers of HIV Infected Babies?”

Healthcare professionals were some of the earliest advocates for women and mothers with HIV. Janet Mitchell [Image 13] was one of those healthcare providers. A title from one of her articles, “What About the Mothers of HIV Infected Babies?” could stand as Mitchell’s foundational question that drove her to become an advocate for HIV-

³⁹⁹ Gena Corea, *The Invisible Epidemic : The Story of Women and AIDS*, 1st edition, (New York: Harper Collins, 1992), 81–82; quote derived from 82; Cindy Patton, *Sex & Germs : The Politics of AIDS*, 1st edition, (Boston : South End Press, 1985.); Triechler, *How to Have Theory in an Epidemic*, 42-98; Goldstein and Manlowe, *The Gender Politics of HIV/AIDS in Women*.

positive women. But Mitchell was also representative of the ways in which many women's-health advocates spoke about, and drew attention towards, the problems associated with HIV-AIDS among poor women of color. In another article she wrote in 1988, "Women, AIDS, and Public Policy," Mitchell's analysis of HIV-AIDS among women exemplified some of the more salient issues women's-health advocates sought to address. She argued that national concerns about HIV among women were too narrowly focused on children and prostitutes infected with HIV. She was concerned that fellow colleagues, such as those in the American College of Obstetricians and Gynecologists, did not prioritize efforts to address HIV among women because the disease primarily affected poor women of color, many of whom were IV drug users.⁴⁰⁰

Mitchell, like many others, articulated the complicated decisions HIV-positive women confronted when considering pregnancy — or if they were already pregnant. She argued that policies which recommended women delay pregnancy, or suggested aborting the fetus, often ignored the "great value" many poor women of color placed on childbearing. As she explained, having a child elevated the "status of a woman" in her community and within her family. That message was especially "devastating" for IV-drug-using women. Having a child, Mitchell wrote, was "the only time when drug-using women [felt] good about themselves," and that pregnancy was a "strong motivator" for women to stop using drugs. More importantly, she argued, if pregnancy was taken away from those women, it eliminated "what little hope" they had. A child provided those

⁴⁰⁰ Janet L. Mitchell, "Women, AIDS, and Public Policy," *AIDS and Public Policy Journal*, 3, no. 2, (1988): 50-52. The title for the section, which is referenced here, is: Janet Mitchell, "What About the Mothers of HIV Infected Babies? National AIDS Network Multicultural Notes on AIDS," *Education & Service*, 1, no. 10, (April 1988): 1-2. In Chapter Three, I also briefly discuss Mitchell's appearance in "AIDS Alley." There, she made similar, critical comments about how her patients were made more visible by the epidemic.

women someone to love and, perhaps just as important, someone to love them.⁴⁰¹ The relationship to pregnancy that Mitchell described was pointedly reflected in an HIV-positive Bronx woman's want to have a child. "I really wanted something of mine," she told an anthropologist, "I don't have nothing in this world...nothing that I really care about."⁴⁰²



Image 13: Dr. Janet Mitchell at Hearing for President Reagan's Commission on AIDS, 1987

In the late 1980s, women's-health advocates also grew concerned about the use of coercive reproductive methods in preventing HIV in children. The most prominent concerns were associated with culturally insensitive and unsympathetic prevention messages, specifically aimed at childbirth, that did not take seriously the cultural realities among poor women of color. But there were more dangerous and coercive methods,

⁴⁰¹ Mitchell, "Women, AIDS, and Public Policy."

⁴⁰² Carol Levine and Nancy Neveloff Dubler, "Uncertain Risk and Bitter Realities: The Reproductive Choices of HIV-Infected Women," *Milbank Quarterly* 68, no 3 (1990): 321 – 351; quote derived from 335.

albeit fringe, suggested at that time as well. At a 1989 Congressional hearing titled *AIDS and Young Children in South Florida*, the sterilization of HIV-positive women was discussed as a potential method for preventing perinatal transmission of HIV. Congressman William Lehman (D-FL) asked panelists — including Gwendolyn Scott and Margaret Oxtoby — “[w]ould you like to see a law that provided sterilization, would that be a solution? ...these are not questions we want to hear, but these are questions that people are thinking about.” After respondents respectively told the Congressman such laws or solutions would be “very discriminatory,” he added “I am just trying to find a solution [to preventing pediatric AIDS], and I think it would be a solution.”⁴⁰³ Public discussions about potentially sterilizing HIV-positive women were not the prime motivator for the rise in AIDS-related women’s-health advocacy, but they were nonetheless reflective of an absence those advocates wanted to correct: the voice of women in public conversations about HIV prevention.⁴⁰⁴

When Mitchell’s article was published in 1988, it was part of a groundswell of activity among women’s-health advocates and activists devoted to the problem of HIV-AIDS among women. From 1987 through 1990, a number of organizations formed and engaged with public-health workers, policymakers, elected officials, and healthcare professionals, in an effort to address HIV-AIDS in women, especially in poor women of color. One of the pillars undergirding those efforts was to challenge what the journalist and women’s-health advocate Gena Corea called “the primacy of the fetus” in HIV-

⁴⁰³ *AIDS and Young Children in South Florida*; quote derived from 45.

⁴⁰⁴ Considering that most of the HIV-positive women were black or Latinx, conversations about sterilization was also unsurprising during these years. See: Roberts, *Killing the Black Body*, 97.

prevention strategies that targeted women.⁴⁰⁵ Most importantly, the grassroots organizations that emerged during this time sought to empower women, through education, so they could make their own decisions about HIV prevention and pregnancy. One of those early organizations formed in New York City: by 1987, the Women and AIDS Resource Network (WARN), which operated out of Brooklyn, began collecting and distributing prevention and other educational specifically geared towards women, work that gained national notoriety. For instance, WARN, which was run by Marie St. Cyr-Delpe, [Image 14] testified at a 1990 Congressional hearing that partially discussed AIDS-funding issues and the problem of HIV among women of color.⁴⁰⁶

⁴⁰⁵ Corea, *The Invisible Epidemic*; quote derived from 47.

⁴⁰⁶ Information about WARN is derived from: *AIDS Funding Issues – Impact AIDS, Early Intervention, Research, and Prevention, March 7, 1990, Hearing before the Task Force on Human Resources*, 101st Cong. (1990) (statement of Marie St. Cyr-Delpe): 52-55; Corea *The Invisible Epidemic*, 58. For another example of how women’s health advocates were addressing the problem of HIV-AIDS among women of color by 1987, see also: The New York State Division for Women *Report of the Public Hearing on AIDS : Its Impact on Women, Children, and Families*.



Image 14: Marie St Cyr-Delpe before Congressional Hearing, April 1990

The growing prominence of women's-health advocacy organizations reflected the increase in national attention towards HIV-AIDS among women, especially women of color. That attention, in part, was the result of AIDS-related activism and advocacy in the late 1980s. ACT UP, for example, had a Women's Caucus: like their gay-male counterparts, the Women's Caucus used visible, public displays of activism to raise awareness about AIDS. In one of their first large public-advocacy initiatives, the Women's Caucus showed up to a New York Mets baseball game on May 4, 1988, Women and AIDS Day. They wanted to show that HIV-AIDS prevention was not just the responsibility of women. The group purchased four hundred tickets to the game, and as the opposing team came to bat for the first time, all four hundred women stood in the stands holding safe-sex banner that read: "Don't Balk at Safer Sex," "AIDS Kills

Women,” and “No Glove, No Love.” They also distributed pamphlets at the entrance to the stadium that informed visitors about AIDS and HIV-prevention. Target towards men, the pamphlet also informed readers that women died from AIDS faster than men, and that “MOST MEN STILL DON’T USE CONDOMS.”⁴⁰⁷

One of the most influential actions taken by the Women’s Caucus was the publication of their AIDS-advocacy and activism guide, *Women, AIDS, and Activism* (1990). Their groundbreaking book, written from an activist perspective, provided a comprehensive account of about the various healthcare, biological, social, and political challenges that women faced in dealing with, and preventing, HIV-AIDS. The book embodied the feminist response to the epidemic that, among other issues, highlighted women’s empowerment surrounding prevention and reproductive choices. It also highlighted how racism and sexism led to and exacerbated the problem of HIV-AIDS among women of color, especially as they related to IV drug use. That particular focus was the result of a growing number of HIV-positive women of color that joined the Women’s Caucus during in the proceeding few years before the book was written and published.⁴⁰⁸

During those same years, in nearby New Jersey, one of the first statewide women’s-AIDS organizations formed. Found in 1988 by the lawyer Rikki Jacobs, and two other women — Ellen Koteen and Diane Palladino — the New Jersey Women’s AIDS Network (NJWAN) became an important and omnipresent organization in the

⁴⁰⁷ Corea, *Invisible Epidemic*, 164-165

⁴⁰⁸ Marion Banzhaf and ACT UP (Organization), eds., *Women, AIDS, and Activism* (Boston, MA: South End Press, 1990). On the influx of HIV-positive women of color into ACT UP, and historical perspective about the Women’s Caucus, see: Brier, *Infectious Ideas*, 172 – 177.

state. They held annual conferences, worked with healthcare providers, acted as a clearinghouse for educational materials, and became part of state-level, AIDS-policy discussions.⁴⁰⁹ NJWAN, like many of the other organizations, provided women with culturally sensitive and gender-specific prevention methods, and they helped women navigate complicated decisions about childbirth and HIV testing. One of the group's earliest informational booklets, *Me First*, tersely summarized NJWAN's central mission, and that of AIDS-related women's-health advocacy: "[t]his is a time for women to think about *themselves*." (emphasis original)⁴¹⁰ Dr. Patricia Kloser, an infectious-disease physician that ran a women's-AIDS clinic at University Hospital in Newark and worked with NJWAN, also spoke about the group's work. Kloser explained that NJWAN members worked locally and nationally to enlist support in educating women about HIV, and they did "an awful lot to get women to empower themselves, to care for themselves."⁴¹¹

By 1990, popular women's publications were also addressing HIV-AIDS among women, especially as related to pregnancy. In November of that year, *Good Housekeeping* ran an article titled "Women, Children, & AIDS: The Latest News," in which the magazine provided women readers with the latest scientific information about AIDS among women. It also explained that children acquired the disease from their HIV-

⁴⁰⁹ New Jersey Women and AIDS Network, "Statement of Philosophy," Box 1, Folder 15 NJ AIDS Collection; Riki Jacobs, Executive Director Hyacinth AIDS Foundation and Co-Founder New Jersey Women & AIDS Network, interviewed by Janet Koch, New Brunswick, New Jersey, March 4, 1994, Rutgers University Special Collections, Medical Library.

⁴¹⁰ *Me First*, New Jersey Women's AIDS Network 2nd Annual Symposium "Confronting the Crisis: the Power of Our Voices, September 17, 1990, Box 3, Folder 12, NJ AIDS Collection.

⁴¹¹ Patricia Kloser, MD Oral History, interviewed by Barbara Irwin, Newark, New Jersey, October 6, 1993, Rutgers University Special Collections, Medical Library; quote derived from 28.

positive mothers in utero, during birth, or from breastfeeding.⁴¹² In April 1990, *Essence* magazine ran an article about how one middle-class Black woman had to make a painfully difficult decisions after testing positive with HIV. The anonymous woman's story was a cautionary tale about knowing one's HIV status. After becoming pregnant, she learned about her HIV-positive status, and the knowledge of her status informed her choice to have an abortion. It was, the woman said, "one of the most painful decisions I have ever had to make."⁴¹³ Adding to that growing visibility were scientific reports detailing the rising trend of HIV-AIDS among women, especially poor women of color. In the summer of 1990, *JAMA* published a study that showed HIV-AIDS was third leading cause of death among women ages fifteen to forty-four. In hard-hit areas, such as New York and New Jersey, death rates from the disease were 29.5 and 40.7 per 100,000 cases, respectively.⁴¹⁴

While NJWAN acted as a state-wide AIDS-education and AIDS-policy lobbying group, the much smaller African American Women United Confronting AIDS (AAWUCA) was dedicated solely to helping women in Newark and other towns in Essex County, New Jersey. Comprised mostly of Black, female volunteers, they also sought to educate women about how best to prevent HIV through safe-sex practices and by avoiding the use of "dirty needles." AAWUCA also spoke about the importance of providing "culturally sensitive" prevention information to women of color, though they did not seem to emphasize that part of the mission, as other organizations did. That was

⁴¹² Linda Holland, "Women, Children & AIDS," *Good Housekeeping*, November 1990.

⁴¹³ Marlene Cimon, "I Tested Positive: A Story Told to Marlene Cimon," *Essence*, April 1990.

⁴¹⁴ Susan Y. Chu, et al, "Impact of the Human Immunodeficiency Virus Epidemic on Mortality in Women of Reproductive Age, United States," *Journal of the American Medical Association*, 264, no 2 (July 11, 1990): 225 – 229; Bruce Lambert, "AIDS in Black Women Seen as Leading Killer," *The New York Times*, July 11, 1990.

certainly due to the fact AAWUCA was not only *of* the community in which they worked, but were Black women themselves.⁴¹⁵

Absent from the group's promotional literature, however, was any mention of preventing pediatric AIDS. That absence was undoubtedly the result of two possible factors: either the narrow focus of AAUCA's work (primary attending to the prevention of HIV among women), or the consequence of a well-known and normalized cultural understanding about the value of bearing children in some poor communities of color (of which Mitchell spoke about in 1987).⁴¹⁶ In other words, AAWUCA did not feel the need to put in writing what their members and target audience already well-understood.

Regardless of whether women's-health organizations specifically addressed issues related to pregnancy and HIV-AIDS, most recognized how the problem of pediatric AIDS disproportionately affected families of color. Groups like NJWAN were committed to challenging the "primacy of the fetus" in local and national prevention efforts, but they were well aware that women of color required information to make educated decisions about childbirth. For instance, one of the local institutions that NJWAN worked with, the Hyacinth Foundation (which largely operated in Northeastern New Jersey), ran a "Perinatal AIDS Prevention Project." The Project, which operated out of Patterson, New Jersey, and predominantly worked with Latina women, represented how women's-AIDS organizations worked to prevent HIV-AIDS among the mother-child family unit.⁴¹⁷

⁴¹⁵ The information about AAWUCA is derived from a small collection of private papers provided to me by one of the group's former members, Gwen Davis. Their mission statement and other information was specifically drawn from: 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.

⁴¹⁶ AAWUCA, "Telling it Like it is."

⁴¹⁷ Hyacinth Foundation AIDS Project News, Vol 2 No 10, November 1990, Box 3, Folder 7, NJ AIDS Collection.

The prevention of HIV among families of color was also promoted by national public-health organizations and leading AIDS experts. In 1991, at a time when AIDS was framed as a “family disease,” leading public-health officials, such as Surgeon General Novello, argued for prevention efforts that dealt “directly with issues of minorities, their culture, and their economic conditions.” In addressing prevention among women of color in poor environments, Novello and her colleagues at HHS also endorsed empowering women as a necessary component in reducing HIV-AIDS among families. They suggested that particular educational programs could “help women and youth at high risk of infection develop a sense of power and control over their lives and their families’ future.”⁴¹⁸ Moreover, much like the activists of NJWAN, Novello and her HHS colleagues emphasized the need for culturally-sensitive educational material in educating women about their vulnerability to HIV.

Regardless of whether women’s-health advocates worked within groups like NJWAN, city hospitals, or large institutions like HHS, they all agreed that women *and* children of color were vulnerable to HIV-AIDS. Groups like NJWAN, and physicians like Janet Mitchell, provided an important counterbalance to pediatric-HIV-prevention efforts that — intentionally or unintentionally — overemphasized the protection of unborn children from the virus. Simultaneously, they also understood that the particular social and environmental conditions of the “the inner city” made women, and their children, especially vulnerable to the “twin epidemics” of IV drug use and HIV.⁴¹⁹ In that

⁴¹⁸ Novello, *Family-Centered Comprehensive Care for Children with HIV Infection*, 23–24.

⁴¹⁹ The “twin epidemics” is derived from the title of the following report: National Commission on Acquired Immune Deficiency Syndrome., *The Twin Epidemics of Substance Use and HIV: Report* (Washington, DC: The Commission, 1991).

respect, women's-health advocates shared a common cause among HIV-harm-reduction professionals: preventing HIV-AIDS from infecting vulnerable families. But with the emergence of AZT as the primary prevention method, efforts to prevent HIV among *families* changed once children were protected from a disease.

Preventing HIV in Children (and Their Families) After AZT

In 1987, pediatric-AIDS healthcare workers and scientists received some promising news. That year, a group of scientists reported the first findings that AZT could prevent perinatal transmission of HIV in mice. The research reinforced earlier and nascent conversations among pediatric-AIDS professionals that saw AZT as a potentially effective prevention method. At the Surgeon General's Workshop on pediatric AIDS in April of 1987, Catherine Wilfert, a pediatric-infectious-disease researcher at Duke University, made a compelling case for using AZT. According to Dr. Arthur Ammann, himself an important biomedical pediatric-AIDS researcher in California, remembered Wilfert's argument. He said that she "reminded everyone that the HIV infection rate of infants was increasing worldwide and, if unimpeded, HIV could become a major cause of early infant mortality." Though he was initially skeptical about giving a toxic drug to pregnant women, Ammann, like many other healthcare professionals, soon supported research efforts to test the safety and effectiveness of AZT.⁴²⁰

Over the next seven years, researchers revealed the incredible effectiveness of AZT in reducing perinatal transmission of HIV. But the announcement of the study and its results were not uncritically received by everyone. Women's-health advocates would

⁴²⁰ Ammann, *Lethal Decisions*; quote derived from 36.

raise concerns about the mother's safety and privacy. Simultaneously, harm-reduction professionals continued to argue for comprehensive efforts to address the problem of HIV among families of color, which continued after 076 trial ended.

Before the clinical trial became public knowledge, scientists had a difficult task of constructing a research protocol for administering a toxic pharmaceutical to pregnant women. Clinical trials involving pregnant women were uncommon, and therefore scientists did not have research protocols on which to base the 076 trial. Between 1987 and 1990, keeping in mind the potential harms that could result from administering AZT to pregnant women, researchers came up with a plan for the trial. They determined that at fourteen weeks after gestation, the fetus would not be harmed by the medication. The women in the trial would then take the medication until they gave birth. At the time of delivery, women would be administered a liquid form of AZT intravenously to ensure that a high level of the medication passed through the placenta and effectively enter the unborn child. After the child was born, she too would be given AZT for six weeks, just in case the doses given before and at birth did not effectively pass through the placenta. Women were also prohibited from breastfeeding their children.⁴²¹

When the proposed trial was announced in 1990, it was met with criticism from women's-health advocates. As Corea explained, the rules for including women in AZT clinical trials had "suddenly changed." When clinical trials for AZT began in the late 1980s, HIV-positive pregnant women were barred. Now, Corea argued, "when the trials offered a theoretical benefit, not to women...but to fetuses, pregnant women were

⁴²¹ The summary of the research protocol is culled from Ammann's account. See: Ammann, *Lethal Decisions*, 35-38. Though he does not provide a clear timeline, this part of his narrative suggests that researchers developed the protocols for the clinical trial sometime between 1987 and 1990.

actively *sought* [emphasis original] for the trials.” Where earlier AZT trials established “strict procedures” excluding women, she continued, now “the women administered AZT in 076 were *required* [emphasis original] to be pregnant.”⁴²² Such critiques continued as the trial started a year later.

When the 076 trial began in early 1991, women in the Newark area were among the first to enter the study. In the spring of that year, UMDNJ issued a press release announcing that the medical school would be one of three sites that were chosen for the trial; the other two were Baylor College of Medicine and University of Miami School of Medicine. The lead investigator, Dr. Edward M. Connor, was an assistant professor of pediatrics at the medical school and he was the associate director of allergy, immunology and infectious diseases at Newark’s Children’s Hospital of New Jersey. He stated in the press release that thirty women were selected for the initial phase.⁴²³ When the announcement of the trial appeared in the newspapers, so too did comments from Marion Banzhaf, Executive Director of NJWAN. In March, she told Joan Whitlow from the *Star-Ledger* that NJWAN did not yet have an official position on the study, but she was “concerned that there are not enough data on the effects of AZT on women to indicate the safety for the women and the babies.” She also told Whitlow: “[t]his trial is not for women; this trial is only about fetuses.” Connor also commented, stating that such concerns were “warranted”, and that the NIH took just over two years to establish safety protocols for the women and unborn children in the trial. Moreover, he added, women

⁴²² Corea, *The Invisible Epidemic*, quote derived from 206.

⁴²³ UMDNJ News Release, “AIDS Clinical Trials Unit to Test whether AZT can prevent Transmission of AIDS virus from Mother to Fetus,” [no date] Box 5, Folder 3; Information about Connor is derived from, Barbara Iozzia, “When the Bough Breaks...” *HealthState: The Magazine of the University of Medicine and Dentistry of New Jersey*, 8, no. 1 (Winter 1990): 32-36, Rutgers University Special Collections, Medical Library.

that had T-cell counts under 200 nevertheless received treatment. He did not say, though, whether those women received AZT.⁴²⁴ Moreover, if a woman's cell count fell below 200 during the study, she was removed due to concerns that she might acquire opportunistic infections.

Calls for equally distributing AZT to HIV-positive women became amplified by the onset of the 076 trial. Like women's-health advocates at the time, some male physicians questioned why all HIV-positive women were not provided AZT. In the summer of 1991, Dr. Cotton [get full name] stated that "most of us feel that women with AIDS and women with fewer than 200 [T-cells], even when pregnant, would benefit from AZT." Dr. Howard Minkoff, who worked in New York City and was an advocate for HIV-positive women starting at least in 1987, argued that standers of care that include the use of AZT "should not be modified based on gender or pregnancy status unless there is compelling scientific need to do so."⁴²⁵ In effect, physicians and women's-health advocates argued for equitable access to *all* possible HIV-AIDS treatment options.

The clinical trial also reignited decades-old worries about the use of Black Americans in biomedical research. Stephanie Garris-Kuiper from AAWUCA told the *Star-Ledger* that her organization was concerned that the studied targeted women of color. "We have every right to be paranoid," she said, "when we don't see a [racially mixed]" group of women in the study. Referencing the Tuskegee Syphilis Study, Harris-

⁴²⁴ Joan Whitlow, "UMDNJ tests AZT in pregnant women to protect fetuses form AIDS," *Star-Ledger*, March 16, 1991, Box 5, Folder 3, NJ AIDS Collection. Joan Whitlow, who was an African American reporter, was one of the few journalists in the Newark-New York City area that consistently reported on AIDS-related issues in the state. Her reporting on pediatric AIDS, specifically, has contributed greatly to my understanding about the epidemic's impact in the state of New Jersey.

⁴²⁵ National Institute of Allergy and Infectious Diseases and the Centers for Disease Control, "U.S. Public Health Service national Conference: "Women and HIV Infection," *Clinical Courier* Vol 9 No 6 August 1991, Box 6, Folder 9.

Kuiper reminded the public that such biomedical studies on populations of color “have not benefited us,” and she questioned why Black leaders were not consulted before the study began accepting subjects.⁴²⁶ The critiques and criticism mounted by AWWUCA and others were not, however, part of a larger movement that sought to halt the 076 trial. Instead, they represented the growing concern among women’s-health advocates that sought to ensure women enrolled in the study were safe and fully informed.

Nevertheless, as 1991 came to a close, New Jersey healthcare workers were encouraged to enroll HIV-positive pregnant women for the second and third phases of the drug trial. At a conference hosted by the New Jersey Medical Women’s Association and the NJ Education and Training Center, healthcare workers received information about the 076 trial that boldly stated the unique opportunity afforded to HIV-positive pregnant women in the state. In a publication produced by the Academy of Medicine of New Jersey, *AIDSline*, the organization mentioned that “[a]t present” the ACTG 076 location in Newark “is **the only facility in the State and one of the few facilities nationwide offering clinical trials for pregnant HIV-infected women** (the bold font was original).⁴²⁷ With recruitment efforts underway, the trial continued over the next few years.

⁴²⁶ Joan Whitlow, “AIDS-pregnancy study stirs more controversy,” *Star-Ledger*, March 19, 1991. For the history and legacy of the Tuskegee Study, see: James H. Jones, *Bad Blood: The Tuskegee Syphilis Experiment*, New and expanded ed. (New York: Maxwell McMillan International, 1993); Susan Reverby, *Examining Tuskegee: The Infamous Syphilis Study and Its Legacy* (Chapel Hill: University of North Carolina Press, 2009).

⁴²⁷ The Academy of Medicine of New Jersey, *AIDSline*, Vol 4, No 1, November 1991, Box 6, Folder 10, NJ AIDS Collection. It is unclear if such recruitment efforts resulted in a racially diverse set of participants in the study. Moreover, and more importantly, this illustrates the enthusiasm many medical professionals had towards the 076 trial – at least in New Jersey.

Meanwhile, by the early 1990s, public-health professionals, harm-reduction advocates, and some elected officials, saw the reduction of HIV among IV drug users as an important way to protect families from the disease. In 1990, the city of New Haven, Connecticut, passed a resolution supporting a comprehensive strategy “to curb the spread of HIV among IVDUs, their sex partners, and children.” That strategy included a needle-exchange program.⁴²⁸ Though they could not pass laws or resolution, organizations like the National Institute on Drug Abuse and the National Commission on AIDS also endorsed and promoted sterile-syringe distribution as an import step in control HIV-AIDS among men, women and children. In their report *The Twin Epidemics of Substance Use and HIV* (1991), the National Commission also argued for additional federal funding that could help curb HIV rates among IV drug users by ensuring more users had access to drug treatment programs.⁴²⁹

The National Commission on AIDS also used part of their findings to critique the George H.W. Bush Administration’s expanding “war on drugs.” In one striking chart, they revealed the large gap in funding allocated for prisons beds versus funds set aside for new drug-treatment slots for fiscal-year 1992. [Figure 18]. Though they did not directly address protecting families from HIV in that specific critique of the Administration’s narcotic-control priorities, a cursory reading of the report suggests how members of the Commission used that opportunity to illuminate how lopsided narcotic-control policies placed vulnerable families at great risk of contract HIV-AIDS.⁴³⁰

⁴²⁸ National Research Council Staff et al., *Workshop on Needle Exchange and Bleach Distribution Programs Proceedings* (Washington, DC: National Academies Press, 1993).

⁴²⁹ National Commission, *The Twin Epidemics of Substance Use and HIV*.

⁴³⁰ National Commission, *The Twin Epidemics of Substance Use and HIV*.

Of course, the Bush Administration was quick to use similar arguments in defense of their war-on-drugs approach. In 1992, the President's Office on National Drug Control Policy (PONDCP) wrote an article that questioned, specifically, the effectiveness of needle-exchange programs. Bob Martinez, the Director of the PONDCP, agreed that the nexus of drug use and HIV was a problem for children and their families. He also agreed that more treatment programs were needed for drug users, especially as an alternative to needle-exchange programs. Most importantly, the article suggested that the Bush Administration's war on drugs was effective in reducing the number of drug users. "Our gains against drug use have been hard-won," Martinez wrote, "and this is no time to jeopardize them by instituting needle exchange programs," which they saw as encouraging further drug use. In other words, for the Bush Administration, the most effective harm-reduction strategy, the one they saw as protecting vulnerable families from the "twin epidemics" of AIDS and drug use, was to continue waging their war on drugs.⁴³¹

⁴³¹ Executive Office of the President, Office of National Drug Control Policy, "Needle Exchange Programs: Are they Effective?: *ONDCP Bulletin* no. 7 (July 1992). The quote from Bob Martinez is derived from the preface of the bulletin.

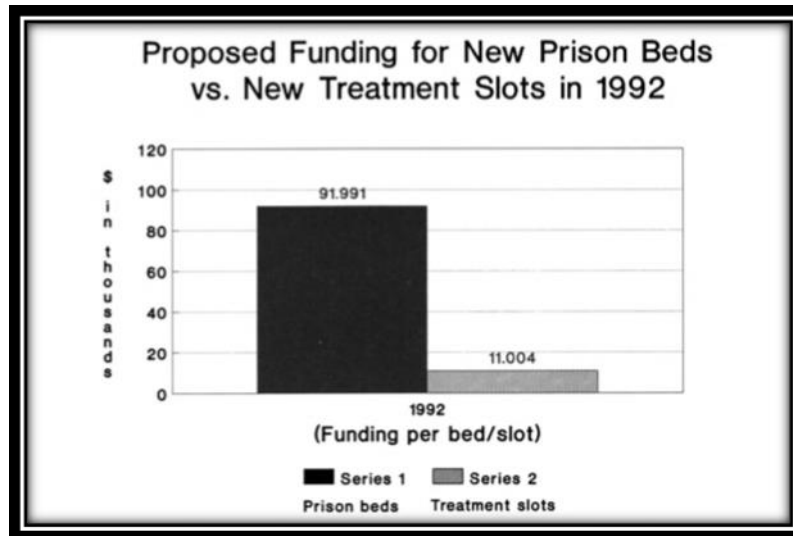


Figure 18: Prison Beds vs. New Drug Treatment Slots, 1992
 Source: The Twin Epidemics of Substance Use and HIV

In 1992, the same year New York City allowed for legal access to clean needles, an AIDS-advisory committee in New Jersey issued a set of recommendations to Governor James Florio. The group was comprised of nurses, physicians, legal experts, elected officials, women’s-health advocates (Marion Banzhaf was one of them), bioethicists, and public-health officials. The group addressed a number of AIDS-related issues, ranging from AIDS care to HIV-prevention strategies. The unequal distribution of HIV-AIDS among poor communities of color was a particularly important focus for the committee. As was common across a number of AIDS-related advisory groups at the national and local levels, the committee in New Jersey argued for better and more comprehensive HIV-harm-reduction strategies for IV drug users. They reminded Governor Florio that 54 percent of AIDS cases in the state were directly the result of IV drug use, which was more than twice the national average. They added that sharing needles was the “most frequent mode of HIV transmission among women and

newborns,” and that the goal of “breaking the link between substance abuse and HIV cannot be overstated.” They, too, recommended more funding for drug treatment programs, and for the state to implement legal, clean-needle distribution programs.⁴³² New Jersey did not adopt policies or laws that provided drug users access to sterile syringes.

New Jersey’s example is important because it reveals the ways in which calls for “saving” the family from HIV — especially its more “innocent victims” — were trumped by the toxic politics surrounding the distribution of clean syringes and illicit drug use. In 1991, health officials in that state compiled a massive and comprehensive “AIDS plan” for addressing the epidemic, in which they embraced the idea that HIV had become a “family disease” in New Jersey.⁴³³ Moreover, New Jersey, especially the urban regions in the northeastern part of the state, had some of the highest rates of HIV-AIDS among IV drug users in the country, much like New York City.. Before and after the state published its first report on AIDS in 1987 — which underscored the problem of HIV among IV drug users in New Jersey — state-level health and governmental officials seriously addressed the pernicious nexus of drug use and HIV-AIDS.⁴³⁴ But, even with overwhelming calls to adopt all potentially useful harm-reduction techniques to prevent

⁴³² Governor’s Advisory Council on AIDS, *Confronting the AIDS Pandemic* (Trenton, NJ: Governor’s Advisory Council on AIDS, 1992); Teri Wurmser, “Needle Exchange Project Recommended for New Jersey,” *New Jersey Nurse*, 23 no. 1 (January 1993): 5.

⁴³³ Recommendations of State Commissioner of Health Frances J. Dunston to Governor Jim Florio, *New Jersey: A State Organizing to Fight AIDS* (Trenton, NJ: New Jersey Department of Health, January 1991), Box 5, Folder 8, NJ AIDS Collection.

⁴³⁴ State of New Jersey Department of Health, *AIDS and New Jersey: A Report* (Trenton, NJ: New Jersey Department of Health, April 1987), Box 2, Folder 4, NJ AIDS Collection; New Jersey Department of Health Prevention Conference, “Health Care Challenges of the 90’s: HIV, Addictions & the Family, June 9 – 11, 1992, Meadowlands Hilton, Secaucus, New Jersey, Box 1, Folder “Health Care Challenges, Department of Health Division of Prevention and Tobacco Control,” NJ State Archives; Frances Dunston, MD, MPH, Former New Jersey Commissioner of Health, oral history, interviewed by Gerry Albarelli, Newark, New Jersey, October 27, 1994, NJ AIDS Collection (hereafter cited; Dunston oral history).

HIV among vulnerable families, New Jersey officials made a political calculus that avoided the legal distribution or sale of sterile syringes during the 1990s.⁴³⁵ Many state officials were sincerely devoted to reducing rates of HIV among children and their families by the early-to-mid 1990s, but not by all means necessary.

The resistance towards, and clarion calls to adopt, sterile-needle distribution is informative beyond the political debates about the efficacy of syringe-exchange programs. By 1993 (and beyond) sterile-syringe-exchange advocates, like Don Des Jarlais, continually struggled against a potent political rhetoric that cast the distribution of clean needles as “promoting drug use.” But in the context of pediatric-AIDS-prevention efforts, harm-reduction strategies writ large, and sterile-needles specifically, were some of the earliest and continuous methods of preventing HIV in entire families since at least 1985. Though not a prevention panacea, the work of harm-reduction specialists represented one of the few attempts in the United States to disrupt the ecology of HIV in American cities by addressing the problem of pediatric AIDS at its root: preventing HIV infection among adult men and women.⁴³⁶ In recognizing that HIV was a “family disease” among drug users, they thus saw the landscape of prevention in broader terms. Understanding that certain behavioral changes were difficult, they tried to intervene early in the chain of transmission, before it reached the family and other members of the community. Of course, biomedical researchers also understood the broader social and environmental problems associated with perinatal HIV transmission, but their solution

⁴³⁵ Dunston, who was the Commissioner of Health at the time, was opposed to syringe exchange programs; see Dunston oral history.

⁴³⁶ Des Jarlais, “Harm Reduction”; Don C. Des Jarlais and Samuel R. Friedman “Missing the Point: Science and Politics in the American Debate on Syringe Exchanges,” *Pediatric AIDS and HIV Infection: Fetus to Adolescent* 4, no. 2 (1993): 61.

offered more targeted, effective, and morally neutral technology that significantly mitigated transmission of HIV to children.

On February 21, 1994, preliminary results from the 076 study were released, showing a drastic reduction in the perinatal transmission of HIV. At that point, the study had expanded to dozens of sites across that United States. The preliminary data, which came from Edward Connor's research team in Newark, was more than encouraging; it prompted researchers and federal regulators to stop the trial, so that AZT could be used in all HIV-positive pregnant women. The results showed that the use of the drug reduced transmission by nearly 68 percent. The results also made immediate headlines. Besides making the nightly news, major papers ran stories about the findings, such as the front-page story in the *Los Angeles Times*, whose headline read: "AZT Found to Protect Fetuses from AIDS."⁴³⁷ Public-health officials and healthcare professionals enthusiastically welcomed the results. In the months following the publication of the results, Len Fishman, New Jersey's Health Commissioner, said that for "the first time we can report that [a] medical intervention has blocked the transmission of HIV infection," and that for [women] who tested positive for HIV, there was now "a treatment that will save the life of [their babies]."⁴³⁸

Martha F. Rogers and Harold Jaffe, top AIDS researchers at the CDC, were also pleased by the findings, but they also reminded healthcare professionals that the

⁴³⁷ CDC *MMWR*, "Zidovudine for the Prevention of HIV Transmission for Mother to Infant," 43 no. 16 (April 29, 1994): 285 – 287; Marlene Cmons, "AZT Found to Protect Fetuses from AIDS," *Los Angeles Times*, February 21, 1994; Emory Thomas Jr., "AZT Found to Sharply Reduce Passage of AIDS from Mothers to their Infants," *Wall Street Journal*, February 22, 1994; Edward M. Connor, et al, "Reduction of Maternal-Infant Transmission of Human Immunodeficiency Virus Type 1 with Zidovudine Treatment," *The New England Journal of Medicine*, 331, no. 18 (November 3, 1994): 1173-1180 .

⁴³⁸ Joan Whitlow, "AIDS Experts Consider the Risks of AZT use by Pregnant Women," *The Star-Ledger*, October 15, 1994, Box 12, Folder 15, NJ AIDS Collection.

medication was no panacea. They spoke about how the use of AZT was not “100 percent effective” in preventing perinatal transmission, that the findings were moot if pregnant women did not know their HIV status, and that further research was needed to understand any potential long-term side effects from using the medication during pregnancy. Caveats aside, Rogers and Jaffe were otherwise quite hopeful the drug would reduce prenatal HIV transmission.⁴³⁹ Undoubtedly, HIV-positive women that were pregnant or wanted to become pregnant were also excited by the news. That sentiment was echoed by Dr. Arlene Bardequez, who worked with HIV-positive women in Newark. Many women who “have been dreaming about becoming pregnant and find out they are HIV positive when they go for parental care,” Bardequez said, were now given hope they could have a child.⁴⁴⁰

But for women’s-health advocates like Marion Banzhaf, the study’s results further reinforced NJWAN’s mission to ensure women were not being coerced into decisions they did not want to make. Between 1994 and 1995, NJWAN addressed two issues related to the use of AZT in pregnant women. The first was related to the still unknown potential side effects the drug might produce in women and children. In *NJWAN News*, the organization published their “Factors to consider about taking AZT during pregnancy.” They included ensuring women had a “full voice in their health care decision-making,” that women were fully informed about the drug’s potential side

⁴³⁹ Martha R. Rogers and Harold W. Jaffee, “Reducing the Risk of Maternal-Infant Transmission of HIV: A Door is Open,” *The New England Journal of Medicine*, 331, no 18 (November 3, 1994): 1222-1223.

⁴⁴⁰ Joan Whitlow, “Study Confirms AZT’s role in cutting mother-to-fetus AIDS transmission,” *The Star-Ledger*, November 3, 1994, Box 12, Folder 15, NJ AIDS Collection.

effects, that healthcare workers did not pressure women into taking the medication, and, perhaps most importantly, that women were not pressured into taking an HIV test.⁴⁴¹

The second issue taken up by women's-health advocates was that of mandatory testing. In the wake of the 076 results, calls for the mandatory testing of pregnant women became a contentious political and policy issue. Before the study results were released, calls for the mandatory testing of newborn children raised similar concerns among women's-health advocates because it essentially exposed the mother's HIV status. Now, with an effective means of preventing HIV in unborn children, calls for mandatory testing grew louder. In the spring of 1995, for example, New Jersey legislators proposed a state law making mandatory HIV testing for pregnant women. The bill did not pass.⁴⁴²

When the CDC issued its guidelines for using AZT among HIV-positive women, mandatory testing was not recommended. In fact, the title of 1995 guidelines, published in the *MMWR*, clearly stated that voluntary testing would become the preferred means by which healthcare and public-health professionals identified HIV-positive women: "U.S. Public Health Service Recommendations for Human Immunodeficiency Virus Counseling and Voluntary Testing for Pregnant Women." In drafting and publishing the guidelines, the CDC assembled a panoply of healthcare professionals, public-health experts, public-health officials, AIDS-advocacy organizations, and women's-health

⁴⁴¹ "State back AIDS drug for HIV pregnant women, *The Times* (Trenton, NJ) April 6, 1994; Joan Whitlow, "State doctors advocates AIDS tests in push for treatment in pregnancy," *The Star-Ledger*, April 19, 1994; Joan Whitlow, "AIDS Experts Consider the Risks of AZT use by pregnant women," *The Star Ledger*, Saturday, October 15, 1994; *NJWAN News* Spring 1994; all preceding newspaper articles and *NJWAN News* is derived from Box 12, Folder 15, NJ AIDS Collection.

⁴⁴² Donna Luesner, "Bill nears law to inform moms-to-be about AIDS, *The Star Ledger*, May 26, 1995; *NJWAN News* Vol 5, No 3, December 1995, Box 12, Folder 23 NJ AIDS Collection. For an overview of the political debates about mandatory testing, see, for example: Goskin, *The AIDS Pandemic*, Chapter 13, "Perinatal Transmission of HIV."

advocates. Marion Banzhaf was one of the over thirty consultants that added to the construction of the guidelines. Besides referencing issues of consent, the guidelines stated that mandatory testing would also result in other negative consequences. For instance, mandating HIV testing might result in women avoiding prenatal care, an important mechanism for identifying HIV-positive women. Over the following years, most states used the CDC guidelines in implementing policies and laws that mandated voluntary, universal testing of pregnant women.⁴⁴³

In the wake of the 076 trials, and with the successful implementation of voluntary testing, public-health professionals and women's-health advocates continued arguing that the most effective means of reducing rates of pediatric AIDS was through the prevention of HIV in women. In an editorial published in the *American Journal of Public Health*, James J. Goedert and Timothy R. Cote claimed that preventing HIV among women was “the ideal strategy” because the “prevention of material infection yields a healthy mother and child,” and that while AZT proved to be an important intervention, it “must not distract us from practices that yield healthy families.”⁴⁴⁴ In the winter of 1995, NJWAN's Michelle O. Badger also argued that “if we look at HIV and pregnancy on a continuum, the issue of AZT would be at the end.” The beginning of that prevention continuum, she further argued, was ensuring women knew their HIV status, regardless of whether they become pregnant, but especially before the woman was with child.⁴⁴⁵

⁴⁴³ CDC *MMWR* “U.S. Public Health Service Recommendations for Human Immunodeficiency Virus Counseling and Voluntary Testing for Pregnant Women,” 44 no. RR-7 (July 7, 1995): 1-15; See also Michael A. Stoto, Donna A. Almario, and Marie C. McCormick, eds. *Reducing the Odds: Preventing transmission of HIV in the United States* (Washington, DC: National Academy Press, 1999), 15.

⁴⁴⁴ J.J. Goedert and T.R. Coté, “Public Health Interventions to Reduce Pediatric AIDS,” *American Journal of Public Health* 84, no. 7 (July 1994): 1065–66.

⁴⁴⁵ *NJWAN News*, Winter 1995

The use of sterile syringes specifically, and HIV-AIDS harm-reduction strategies for IV drug users more broadly, continued to be recommended as a means of protecting families from the disease. In 1995, the National Research Council and the Institute of Medicine published a report that argued for the prevention of initial HIV infections among IV drug users, especially men. If efforts were not taken to stop initial infections, the report stated, “an injection drug user...with HIV can cause a cascade of new infections ...through needle sharing, sexual transmission, and perinatal transmission.”⁴⁴⁶ From 1995 through 1997, New Jersey legislators and public health officials attempted to enact legal needle exchanges, arguing it would protect IV drug users and their families, but to no avail. In the fall of 1997, there was even a demonstration at the New Jersey Statehouse, comprised mostly of mothers and grandmothers, demanding the state institute policies that provided users with sterile needles. At the rally, one woman mentioned the devastating impact HIV-AIDS had on her family. Flettie La Coste Spruill told the *Star-Ledger* that she lost four sons, a godson, and two stepsons to “the virus.”⁴⁴⁷ Though New Jersey had some of the highest rates of HIV-AIDS among IV drug users, legal access to sterile syringes would not occur in the state until 2006.⁴⁴⁸

By the late 1990s through the early 2000s, discussions about protecting families from HIV-AIDS essentially, and perhaps unsurprisingly, had all but disappeared with the

⁴⁴⁶ Normand et al., *Preventing HIV Transmission*; quote derived from 44.

⁴⁴⁷ Gale Scott, “Clean-Needle Program Quietly Makes Rounds,” *The Star-Ledger*, September 21, 1995; Senator Wynona M. Lipman, “Ease Restrictions on Syringe Sales,” *The Star-Ledger*, September 21, 1995; Box 12, Folder 12, NJ AIDS Collection. Donna Leuser, “Panel Recommends Needle Program Whitman Opposes,” *The Star-Ledger*, April 4, 1996, Box 13, Folder 12, NJ AIDS Collection. The information – and quote – about the rally at the New Jersey Statehouse, see: Donna Leuser, “Mothers who Lost Kids to AIDS Cry out for Clean-Needle Effort,” *The Star-Ledger*, October 22, 1997, Box 13, Folder “News Articles 1996-1999,” NJ AIDS Collection.

⁴⁴⁸ Information about New Jersey’s legal exchange programs established in and after 2006 is derived from: Chase, *Surviving HIV/AIDS in the Inner City*, 187-188.

rise and success of AZT. In 1999, the Institute of Medicine (IOM) and National Research Council (NRC) published a comprehensive report detailing how voluntary, universal testing of pregnant women, coupled with the use of AZT for those found to be HIV-positive, proved to be successful in reducing overall rates of pediatric AIDS. The report, titled *Reducing the Odds*, further recommended that one of the most effective means of preventing pediatric AIDS was through stopping the initial infection in women. That included reducing HIV rates among IV drug users, though needle exchange was not recommended. But in the larger context of the report, preventing HIV among families was not a significant focus.⁴⁴⁹

What also became clear by this period was that rates of pediatric AIDS were declining before the results of the 076 trial were published. Though AZT was a significant intervention, the IOM-NRC report showed that there was a 17 percent decline in the number of children born to HIV-positive mothers before the use of AZT. In fact, rates of perinatally transmitted cases of HIV were declining between 1992 and 1995, both nationally and in places such as New York City, which experienced some of the highest number of cases. Some public-health research also suggested that around the same time, looking at New York City specifically, the number of HIV-positive IV drug users was also on the decline, a trend which continued through 2001. Whether those declining numbers were directly linked the reduction in perinatally acquired HIV-AIDS is

⁴⁴⁹ Stoto, Almario, and McCormick *Reducing the Odds*. The primary mandate for the IOM-NRC report was to comprehensively analyze the effectiveness of testing and counseling efforts, as they related to preventing perinatally transmitted HIV. This was the result of changes in the Ryan White CARE Act that proposed making funds contingent on a state's implementation of mandatory newborn HIV testing. But given their specific mandate, the report is still, nonetheless, reflective of how public health professionals were no longer using the protection of the family in their discussions about HIV prevention among children.

unclear.⁴⁵⁰ But the declining rates of children born with the disease nevertheless suggest that prior to the results of the 076 trial (and the implementation of the CDC guidelines), early prevention efforts, coupled with the action of women themselves, resulted in some of the initial declining numbers before 1995.

The most precipitous decline in perinatally transmitted HIV came after 1995, but the successful reduction of pediatric AIDS cases was not the result of AZT alone. As part of their analysis, the IOM-NRC report included a site-visit summary of locations in New York City and New Jersey. One of the places highlighted in the summary was the FXB (CHAP) team, which had just resettled at UMDNJ. The analysis concluded that the success of reducing perinatal transmission was the result of four major elements. They included research funding and infrastructure; maternal health care and newborn counseling; healthcare financing; and the routine use of HIV counseling that was integrated into models of care. Most importantly, the researchers stated that the programs visited “repeatedly [ascribed] their success to the vigorous efforts of specially trained counseling staff (e.g. nurses, counselors, and social workers). These professionals were responsible for the bulk of HIV counseling to encourage patients to accept testing and treatment.” They also used the FXB Center as an exemplar to illustrate how the dogged

⁴⁵⁰ Information is derived from: Stoto, Almario, and McCormick *Reducing the Odds*; The New York City Department of Health, Office of AIDS Surveillance, *Children perinatally exposed to HIV in New York City: Semiannual Surveillance Update, November 1999*, New York City Municipal Archives; Don C. Des Jarlais et al., “‘Informed Altruism’ and ‘Partner Restriction’ in the Reduction of HIV Infection in Injecting Drug Users Entering Detoxification Treatment in New York City, 1990–2001,” *JAIDS Journal of Acquired Immune Deficiency Syndromes* 35, no. 2 (February 1, 2004): 158–166; Vicki B. Peters et al., “Trends in Perinatal HIV Prevention in New York City, 1994–2003,” *American Journal of Public Health* 98, no. 10 (October 2008): 1857–1864; U.S. Health and Human Services, Health Resources and Services Administration, “Child Health USA 2012,” accessed August 1, 2020, <https://mchb.hrsa.gov/chusa12/hs/hsc/pages/pha.html>.

work of the counseling staff, work that was “labor-intensive,” produced results.⁴⁵¹ Here, the development and maintenance of the system of care that was influential in treating children with HIV-AIDS before the advent of ARTs became an important system for the prevention of pediatric AIDS as well.

The actions of pregnant women, most notably, were also credited for the decline in perinatally transmitted HIV. Pregnant women, researchers showed, were much more likely to get tested for HIV than non-pregnant women. In part, that was the result of the relationship between patients and their counselors. One woman in New York, “Tanya” (pseudonym), was an IV drug users and mother of four. At first, she did not want to get tested, but because of her “nurse’s assurance that she was not alone,” and that the test results would benefit the mother and baby, Tanya agreed to get the test. “If it weren’t for my nurse,” she told researchers, “I wouldn’t have gotten tested.” Mothers-to-be also decided to get tested because they wanted a healthy child. “Virtually all patients described their newborn’s health, before their own, as their overarching reason for proceeding with testing and treatment,” researchers reported. For the IOM-NRC researchers, such evidence helped them argue that voluntary testing — over mandatory testing — was the best way to ensure HIV-positive women agreed to use AZT.⁴⁵² But the agency of those mothers is also important when considering the success and effectiveness of pediatric-AIDS prevention. Coupled with the labor of counseling staff, we see that the drug’s preventive potency was only as good as the people who provided, and decided to receive, the medication.

⁴⁵¹ Stoto, Almario, and McCormick, *Reducing the Odds*. See: "Appendix E: New York/New Jersey Site Visit Summary"; quote derived from 237.

⁴⁵² Stoto, Almario, and McCormick *Reducing the Odds*; quotes derived from 328 and 246.

In 2001, the CDC evaluated the success of using AZT in the prevention of perinatal HIV. They reported that the numbers of children born with HIV continued to decrease. Over the next several years, those numbers continued to grow in smaller.⁴⁵³ In that same report, the CDC also indicated that between 1993 and 1996, pregnant women diagnosed with HIV increased from 70 to 80 percent. As the twenty-first century entered its second decade, HIV continued to disproportionality affect women of color, especially Black women, though the overall numbers of women diagnosed with HIV declined.⁴⁵⁴ But when looking to the 2001 CDC report, its further revealing when considering how the introduction of AZT changed how public-health professionals understood the problem of HIV in women and children. Since HIV-positive women were the primary “risk factor” for children acquiring the disease, the “HIV/AIDS epidemic in children,” the report stated, “closely paralleled the epidemic in women until the mid-1990s.”⁴⁵⁵ What began as prevention efforts to halt HIV infection in women *and* children in the mid-1980s, transformed into two separate efforts by the mid-1990s — and beyond.⁴⁵⁶

⁴⁵³ Helene D. Gayle, et al “Successful Implementation of Perinatal HIV Prevention Guidelines” *MMWR*, (May 11, 2001): 15-28; HRSA “Child Health USA 2012,” <https://mchb.hrsa.gov/chusa12/hs/hsc/pages/pha.html>.

⁴⁵⁴ Donna Hubbard McCree, et al, “Changes in the Disparity of HIV Diagnosis Rates Among Black Women – United States, 2010 – 2014,” *MMWR*, 66 no. 4 (February 3, 2017): 104-106, accessed August 1, 2020, <https://www.cdc.gov/mmwr/volumes/66/wr/mm6604a3.htm>.

⁴⁵⁵ Helene, “Successful Implementation of Perinatal HIV Prevention Guidelines.”

⁴⁵⁶ Note to reader: This is not the conclusion – this is a placeholder. I am unsure if the material I want to add here will go in the Epilogue or if it works better for the conclusion of this chapter. Also, the Epilogue will be submitted with the deposit copy.

EPILOGUE

From 2001 to 2010, the number of children born with HIV continued to decline. During these years, the preventative potency of AZT had become a welcome biomedical intervention for healthcare professionals and parents alike. By 2010, roughly two-hundred and seventeen children, under the age of thirteen, were diagnosed with HIV. That same year, twenty-three children were diagnosed with AIDS [Figure 19].⁴⁵⁷ For healthcare professionals and public health experts, specifically, the reductions in new cases of perinatally acquired HIV represented an important success. Encouraged by the use of ARTs in preventing pediatric AIDS, pediatric-healthcare providers, scientists, and public health professionals even set a goal to eliminate the perinatal transmission of HIV in the United States.

In 2012, the details of that initiative were published in *Pediatrics*. According to the article, between 2006 and 2008, public health professionals and pediatric-AIDS advocates established a three-point approach for eliminating HIV-infection among children. First, they sought to standardize biomedical interventions and policy changes that supported what they called the prevention of mother-to-child transmission of HIV (or PMTCT). Second, they promoted the routine screening of pregnant women for HIV. Third, and “most critically,” they argued for more national attention and resources directed towards the “primary prevention of HIV in women.” Though the prevention of HIV in women was noted as an important part of their larger goals by 2012, the use of

⁴⁵⁷ HRSA “Child Health USA 2012,” CDC, *HIV Surveillance Report*, “Diagnosed HIV Infection and AIDS in the United States and Dependent Areas, Vol. 22, 2010.

ARTs remained the cornerstone, techno-scientific tool in this new effort to eliminate the perinatal transmission of HIV. But, as the authors noted, a true elimination of pediatric AIDS in the U.S. was not “feasible.” Instead, their definition of “eliminating” perinatal transmission of HIV was predicated upon a goal of reducing the number of cases to well below one-hundred per year.⁴⁵⁸

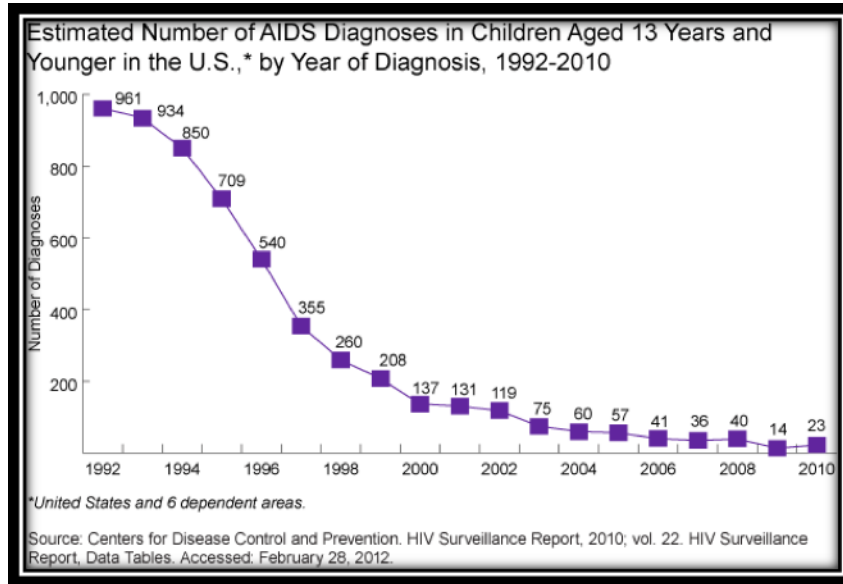


Figure 19: Declining Numbers of Pediatric AIDS Cases, 1992-2010
Source: HRSA’s “Child Health USA 2012”

Over the next several years, the numbers continued to decline, though it is difficult to link the continued declining rates of pediatric AIDS cases to such “elimination” initiatives. Nevertheless, in 2017, for example, the CDC reported that only thirty-nine children were diagnosed with perinatally acquired HIV. The stark decline was

⁴⁵⁸ Steven Nesheim et al., “A Framework for Elimination of Perinatal Transmission of HIV in the United States,” *Pediatrics* 130, no. 4 (October 1, 2012): 738–44. For the CDC’s revised testing recommendations in 2006, see: [put in correct info] “Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-Care Settings” 55 (2020): 22. As of 2019, the CDC is continuing their efforts to eliminate perinatal transmission of HIV. In many ways, their framework is similar to what was proposed in 2012. See: “Elimination of mother-to-child HIV Transmission (EMCT) in the United States, accessed August 1, 2020, <https://www.cdc.gov/hiv/group/gender/pregnantwomen/emct.html>.

particularly impressive in the places that saw the highest numbers of pediatric AIDS throughout the epidemic. In the states that initially and continually saw high numbers of pediatric AIDS through the epidemic: Florida reported nine new cases, New York reported one case, and New Jersey reported zero new cases. Though we cannot link such low numbers to any one single pediatric-AIDS prevention initiative, it is safe to assume that the testing of pregnant women for HIV, coupled with the use of ARTs, proved important in the continued reduction of new cases of HIV among children.⁴⁵⁹ As we saw in chapter five, much of that success was the result of teams of nurses and social workers, as well as pregnant women who sought to ensure their children were not born with HIV.

Though the numbers of new cases remained low through the first decades of the twenty-first century, the story of pediatric AIDS remains one of inequality. In the same 2012 article that detailed how the nation can drastically reduce and retain low number of new infections among children, the authors noted that the “degree of health inequality seen in the perinatally infected population is even greater than that among adults.” Black children remained disproportionately infected with HIV, which was the result of “tight social and sexual networks and poverty.”⁴⁶⁰ In 2017, for instance, the CDC reported that roughly 70 percent of children born with HIV were Black.⁴⁶¹ Given the long history of racialized health disparities in the United States, such health-related inequalities are undoubtedly unsurprising. Yet the consistency of such disparities, particularly within the

⁴⁵⁹ CDC, “Diagnoses of HIV Infection in the United States and Dependent Areas, 2018: Children Aged <13 Years,” accessed August 1, 2020, <https://www.cdc.gov/hiv/library/reports/hiv-surveillance/vol-31/content/children.html>. Nesheim et al., “A Framework for Elimination of Perinatal Transmission of HIV in the United States,”

⁴⁶⁰ Nesheim et al., “A Framework for Elimination of Perinatal Transmission of HIV in the United States,” 739.

⁴⁶¹ CDC, “Diagnoses of HIV Infection in the United States and Dependent Areas, 2018: Children Aged <13 Years.”

context of the history of HIV-AIDS in the United States, nonetheless reminds us just how closely linked pediatric AIDS was, *and is*, to the problem of poverty – a problem that also continues to place women of color at increased risk of HIV infection.⁴⁶²

In many ways, the history of pediatric AIDS in the United States is a story about the deleterious health effects associated with urban poverty during the late twentieth century. As we have seen, the economic, social, and physical changes that occurred in American cities between 1950 and 1980, factored significantly in the creation of an urban ecology that concentrated pediatric AIDS in particular places. Two of the most important structural conditions in those places—concentrated poverty and racialized segregation—especially helped spread and exacerbate the problem of HIV-AIDS among children and their families.

Of course, those living in poverty have historically been disproportionately affected by particular disease phenomena; but the emergence of pediatric AIDS in the 1980s also reminds us how poverty, again, became the object of political discussions among healthcare and public health professionals. As those healthcare and public health professionals rediscovered the health effects of poverty, they often underscored how the problem of HIV would not be simply remedied through educating Americans about avoiding “risky” behaviors. According to a 1988 Congressional report, which referenced James Oleske’s experience in Newark, “...prevention cannot be limited to education and behavior change alone.” Quoting Oleske, the report stated that “[h]is experience in

⁴⁶² Donna Hubbard McCree, et al. “Changes in the Disparity of HIV Diagnosis Rates Among Black Women — United States, 2010–2014,” *MMWR* 66 (2017): 104-106, <https://doi.org/10.15585/mmwr.mm6604a3>.

Newark has demonstrated that ‘AIDS is a disease of poverty and drug abuse, and until we address these larger issues, we won’t really solve the problem of AIDS.’”⁴⁶³

Through the late 1980s and the 1990s, scholars, public health scientists, and AIDS-prevention advocates, also made similar claims. In some cases, they also suggested how HIV-AIDS prevention initiatives should incorporate poverty-mitigation efforts that included better access to housing, healthcare, and employment in communities of color.⁴⁶⁴ When considering the prevention of pediatric AIDS during the 1990s, such poverty-mitigation strategies were not, however, seriously considered by health policymakers. In this respect, the history of pediatric AIDS in the U.S. further illuminates a persistent historical continuity related to racialized health disparities in twentieth-century America: that is, how such socio-environmental and economic improvement strategies are continually proposed, discussed, and researched—but are rarely implemented.

In the end, however, the history of pediatric AIDS in the U.S. does not simply represent one more historical case study about how some children and families of color have been disproportionately affected by the combined problems of poverty and health inequalities. Instead, the story of pediatric AIDS provides us an important reminder about the ways in which our nation continually prioritizes biomedical, disease-prevention efforts over public health initiatives that address the important—albeit complicated—underlying conditions that result in the unequal distribution of childhood-disease

⁴⁶³ *Continuing Jeopardy*, 10.

⁴⁶⁴ See, for example: *AIDS: Its Impact on Women, Children, and Families*, 41-43; Anne-Emanuelle Brin, et al, “Pediatric AIDS in the United States: Epidemiological Reality Versus Government Policy,” *International Journal of Health Services* 20, No. 4 (October 1, 1990): 617-630; Wallace, *A Plague on Your Houses*; 123-136; 185-194.

problems, such as HIV-AIDS. The pediatrician Max Seham trenchantly and presciently captured this historical continuity in 1970. Influenced by the second great racial reckoning in the nation's history, the Civic Right Movement, and how poverty continued to affect the health of Black children in the U.S., Seham wrote: "what is urgently needed now are not more conferences for basic research but rather a frontal attack on poverty and its associated evils."⁴⁶⁵

Of course, the architectures and products of biomedicine provided an important solution to the problem of perinatally acquired HIV. The advent of ARTs during the mid-to-late 1990s proved effective in saving children from contracting HIV infection, but their use and success had a paradoxical effect: the "biomedical-progress" narratives that accompanied these advances unintentionally undermined alternative prevention efforts that sought to mitigate the social, economic, environmental, and healthcare problems that put children at risk of HIV-AIDS in the first place. In this respect, such techno-scientific remedies represent another half-measure solution for a disease problem that resulted from structural inequalities that have been built into particular American landscapes. As our nation copes with yet another "new" infectious disease pandemic, one that affects children and adults alike, the history of pediatric AIDS reminds of the benefits *and* burdens associated with the biomedical solutions to complicated health problems. As the history of pediatric AIDS reveals, such solutions are *important*, but their success should not overshadow the larger, underlying social, economic, and environmental problems that are not easily remedied by a techno-scientific fix.

⁴⁶⁵ Seham, "Poverty, Illness, and the Negro Child," 310.

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