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# Responding to an Ever Changing Epidemic: The Evolution of HIV Care in New Haven

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## Preface

The HIV/AIDS epidemic has been a new event in human history and has had deep and broad effects on individuals, communities, and institutions in the US and globally. New Haven is representative of urban centers in the US in which the HIV/AIDS epidemic exploded in the early 1980s and subsequently matured to a chronic disease affecting predominantly underserved, minority populations. The institutional and community response to the epidemic has historically encompassed the intertwined partnerships between Yale based institutions (particularly, Yale School of Medicine and Yale New Haven Hospital) and New Haven community-based agencies, and has evolved through the past 30 years to keep pace not only with dramatic scientific and clinical advances, but also changes in health care delivery.

## Introduction

The first cases of AIDS were reported in Connecticut in 1981, coincident with the initial reports in New York City and San Francisco. Since then, through 2014, 20 997 HIV/AIDS diagnoses have been reported in Connecticut.

New Haven is the second largest city in CT with an estimated population of 130 322 (US Census 2015). Of the 10 727 prevalent HIV/AIDS cases in CT reported through 2014, 1452 (13.5%) reported residence in New Haven at the time of diagnosis, ranking the city second behind Hartford. Currently, the demographic profile of prevalent cases in New Haven is predominantly one that affects the urban poor (in New Haven 28.8% of residents live below poverty level). Specifically, 77% of HIV cases have occurred in persons of color, 36% acquired HIV through injection drug use (IDU), and 24% through men having sex with men (MSM). Among newly diagnosed cases in 2014, 85% were among persons of color; in contrast to longer standing prevalent cases, among these newly diagnosed cases, 65% were among MSM while only 3% were acquired through IDU.

There is a long, complex, and successful history of response to the HIV/AIDS epidemic in New Haven, involving Yale New Haven Hospital (YNHH), Yale University School of Medicine (YSM), the City of New Haven, and community agencies. This history has evolved over time and has included periods of conflict and uncertainty, exemplified by challenges of "town-gown" divides, debates over how care should be delivered even as therapies and the healthcare landscape changed, demands of research vs clinical care, interagency turf battles in the setting of scarce resources, as well as genuine and successful efforts at collaboration. The overarching and unifying theme has been an ongoing commitment to providing comprehensive and humane clinical care that has focused on the special needs of this patient population.

## The Early Years: 1981 – 1990
### Response from the Medical Community

The first decade of HIV/AIDS predominantly consisted of response to an epidemic crisis by first responders from the medical and medically-allied professions. The first person with recognized AIDS was diagnosed in 1981. During the 1980s, New Haven was among the 12 most heavily impacted cities affect-

GERALD FRIEDLAND, MD is a seminal figure in the history of the HIV epidemic who has shaped practice with his pioneering epidemiological studies at the beginning of the epidemic. He came to Yale in 1992 to become the first HIV/AIDS Program Director. MERCEDITAS VILLANUEVA, MD completed an Infectious Diseases fellowship at Yale in 1995, has practiced in the HIV field for over 20 years and is the current director of the Yale HIV/AIDS Program. In this piece, both authors recount the three-decade evolution of the New Haven response to the HIV/AIDS epidemic as they experienced it and reflect on the important lessons they learned about the importance of community collaboration. *Corresponding author*: Merceditas Villanueva, MD, merceditas.villanueva@yale.edu

ed by AIDS in the United States. Unlike the wave of initial cases reported in other cities that were largely seen in white men having sex with men, New Haven cases were from disproportionately affected racial and ethnic minorities. In the initial years, the epidemic resulted in a concentration of inpatients at YNHH with advanced AIDS and opportunistic conditions; given the demographic of poor and often homeless patients, the hospital became an inpatient hospice, housing large numbers of dying patients.

The early response was characterized by a group of health care workers including physicians, nurses, and social workers, who cared for patients scattered throughout the hospital. In 1987, YNHH Chief of Staff John Fenn, together with the hospital's Bioethics Committee, required its doctors to treat AIDS patients as an expectation for continuing reappointment. On the outpatient side, an informal multidisciplinary group of clinicians and other health care workers banded together to provide volunteer care for patients with AIDS. The group met once a week in what was known as the Dana 3 Clinic.[1]

### Community Response

There was a remarkable response of local community agencies in the early days of the New Haven epidemic, catalyzed by a perception that state and city government were not addressing the epidemic in a timely and effective fashion. AIDS Project New Haven (APNH) was the first organization to be established in 1983, led by Dr. Alvin Novick, Professor of Ecology and Evolutionary Biology at Yale, in response to the devastating impact of AIDS within the gay community. Subsequently, the Mayor of New Haven (Mayor DeLieto) appointed the Mayor's Task Force on AIDS in June 1986, with the purpose of assessing the long- and short-term impact of the disease and to bolster existing AIDS education, risk reduction, and prevention programs. Members of this task force included representatives from multiple city and community agencies as well as YSM and YNHH personnel.

APNH was perceived as serving predominantly the white gay community, whereas the HIV/AIDS epidemic was clearly much broader in its individual and community impact. In 1987, under the leadership of the late Mrs. Elsie Cofield, a retired elementary school teacher and prominent member of the Immanuel Baptist Church, the AIDS Interfaith Network was formed to serve the African-American community. In 1988, Hispanos Unidos Contra el SIDA was founded with targeted outreach towards the Hispanic community.

In summary, the first decade was characterized by widespread fear of a uniformly fatal and stigmatizing disease. Lack of medical treatments galvanized an eclectic group of medical professionals to provide care even as they were learning the natural history of AIDS. Community agencies were critical partners in providing education, palliative care, and social services to dying people. As noted by June Holmes, an early social worker involved in the epidemic, "beyond the hospital walls, we rely on the community."

### The Second Decade: 1991 – 1999

In 1992, AIDS had become the leading cause of death among adults between 25 and 44 years old. New Haven was one of 15 cities in the US in which this was true not only for young men, but for young women as well, with consequent challenging issues of mothers and children with HIV. Advances had been made in the provision of diagnosis, prevention, and treatment of the opportunistic infection complications of HIV infection as well as the organization of care. Highly active antiretroviral treatment (HAART) became available in 1996 and within a year, AIDS deaths had fallen by 40%.

### Response from the Medical Community

By 1990, the length of stay for HIV/AIDS patients at YNHH peaked at 17.3 days. Many patients remained hospitalized for months, essentially living at YNHH due to lack of insurance and inadequate housing options in the community. In 1991, YNHH conducted a study to investigate resource utilization by AIDS patients that found that 30% of patient days were unnecessary due to a lack of skilled nursing facilities, hospice, home care, and other housing opportunities. The study concluded that community-based support such as case management, meals, home health care, and transportation, was needed to decrease dependency on inpatient care. In conjunction with the creation of the Children's Hospital, YNHH allocated $500,000 in seed money in the form of grants for community organizations to develop programs that could reduce hospitalization and costs associated with AIDS care. Recipients of these funds included Leeway (a skilled nursing facility), Hispanos Unidos, AIDS Interfaith Network, VNA, and AIDS Project New Haven, among others. YNHH was later recognized by the National Hospital Association with the NOVA Award for its collaborative community efforts.

Dr. Gerald Friedland was recruited as the first Director of the YNHH AIDS Care and YSM AIDS Program in 1991 to expand the Hospital AIDS program and strengthen the necessary community, hos-

pital, and medical school resources that were essential in the face of the growing epidemic. Additional funding was allocated by the hospital to provide for the expansion of the HIV clinic with hiring of additional social workers, physician assistants, mental health professionals, a dedicated inpatient AIDS social worker, and program administrative support. The Nathan Smith Clinic, a YNHH-based clinic, was established in 1991 as the first dedicated AIDS Clinic in CT. In addition, a designated HIV/AIDS inpatient unit linked closely with the clinic was established and staffing enriched to provide improved care for this challenging population.

Under the leadership of Dr. Friedland, YSM began to mobilize its research efforts. Prior to coming to Yale, Dr. Friedland had published a landmark study in the *New England Journal of Medicine* that debunked the prevailing notion that AIDS could be spread by casual contact. One of the first highly publicized research efforts grew out of a partnership between the City of New Haven's Mayor's Task Force, YSM, Yale Epidemiology and Public Health, and the School of Management. This study provided the first definitive evidence that needle exchange could directly reduce the spread of AIDS without a concomitant rise in the rates of drug addiction. In 1992, the AIDS Program was awarded an NIH Adult AIDS Clinical Trial Unit to conduct trials with new AIDS drugs with a focus on recruiting minorities, women, and intravenous drug users. The Pediatric AIDS Program directed by Dr. Warren Andiman played a key role in the landmark study that demonstrated the role of AZT in preventing mother-to-child transmission. Further community-based research spawned novel health care delivery programs such as the Community Health Care Van and the HIV in Prisons Program established by an early faculty member, Dr. Frederick Altice.

**Community Response**

The early advocacy work spearheaded by the Mayor's Task Force had further outgrowths including obtaining a successful Ryan White planning grant for capacity building in 1991, followed by the formal designation of New Haven as an Eligible Metropolitan Area in 1993. This led to New Haven/Fairfield Counties becoming the successful recipient of Ryan White Part A funds in 1995 with Tom Butcher as its first Program Director. Early recipients included community-based agencies (APNH, Hispanos Unidos, AIDS Interfaith) as well as the two federally qualified health centers, Cornell Scott Hill Health Center and Fair Haven Health Center. The Hospital of St. Raphael established its own AIDS Clinic (the Haelen Center). It is an interesting historical fact that YNHH and YSM made a tacit agreement with community agencies that they would not compete for Ryan White funding, in part, due to a perception that Yale had sufficient alternative clinical and research resources. In retrospect, this arrangement, which embodied issues of the "town-gown" divide, while initially benefitting community agencies from a financial standpoint, may have inadvertently led to delays in promoting the necessary dialogues between the medical establishment and community-based AIDS service organizations. This would lead to further changes in the next decade.

**The Third and Fourth Decades: 2000 – 2016**

The third decade saw the continued introduction of new antiretroviral medications, including fixed dose combinations and more potent agents with improved side effect profiles, that have resulted in improved longevity and quality of life for persons living with HIV. This resulted in a shift from HIV/AIDS being a serious life threatening condition to a chronic disease. The inpatient AIDS ward at YNHH was no longer filled with desperately ill AIDS patients and clinical activity shifted to the outpatient setting. Additional clinicians were recruited to join the clinical team. The research focus expanded with successful grant funding. Domestic research in substance abuse focused on community-based interventions that addressed both structural and behavioral issues that affect individuals with, or at risk for, HIV. Educational initiatives expanded including the development of an HIV training track led by Dr. Lydia Barakat and the incorporation of the AIDS Education Training Center grant led by Karina Danvers. A diverse group of new faculty and other colleagues expanded the clinical and research scope of the AIDS program.[2]

This time period has seen a shift in focus of HIV/AIDS from a domestic to a global issue, reflected in new clinical and research efforts. Dr. Friedland's work, now in collaboration with Dr. Sheela Shenoi, expanded to South Africa and the integration of HIV and TB prevention and treatment as a strategy for introducing antiretroviral therapies and improving the outcome of both diseases. This led to the discovery of extensively drug resistant tuberculosis almost entirely among persons co-infected with HIV. Expansion of international research efforts by Dr. Altice have included work in Ukraine, Malaysia, and Peru focusing on evidence-based interventions to control the new waves of HIV in developing countries.

In 2009, Dr. Merceditas Villanueva was recruited as AIDS Program Director. Her first priority was to

strengthen and expand the Ryan White funded network of providers in New Haven. In the past, Ryan White funds served as a payor of last resort for uninsured individuals as well as funding support services such as palliative care. However, with the growing emphasis on the medical model of HIV care and an emphasis on data-driven quality management programs, it became necessary to formally include the largest outpatient and inpatient providers of HIV and AIDS services (YNHH and the Hospital of St. Raphael's were merged in 2012) within the Ryan White network in New Haven. Coincidentally, in 2009, the Ryan White Part A office stipulated that only one lead agency could apply for funds on behalf of contributing agencies. Under Dr. Villanueva's leadership, YSM assumed the role of lead agency.

The adoption of this model required a transformation of the relationship between YSM/YNHH and community agencies into one of formal cooperation built on the unique strengths each agency contributed. This arrangement was initially contentious given the history of "town-gown" tensions. However, given the reality of joint funding, a local governance structure with a community-wide database to track service delivery and quality measures has transformed the previous silos of care built historically along racial, ethnic, and institutional lines. This evolution to "self-government" has been challenging at times as the group learned to forge a joint identity and to make hard decisions regarding resource allocation; over time, this resulted in defunding of certain agencies. Nonetheless, the process has also been rewarding. Under this model, progress towards achievement of public health goals articulated by the National HIV/AIDS Strategy could be assessed within a formalized infrastructure. These goals converge on critical public health issues defined in the HIV treatment cascade model which measures progress according to the care system's ability to link, engage, retain in care, and suppress HIV viral load among persons living with HIV. The lead agency model in New Haven has paved the way for additional collaborations, including one with the CT Department of Public Health (DPH), to study interventions that can improve health outcomes in persons living with HIV statewide.

## Conclusions and Lessons Learned

As the HIV/AIDS epidemic continues into its fourth decade, the challenges faced in New Haven mirror those of the rest of the country and the world. The advances of modern medicine have still not been made accessible to all persons living with HIV for many different reasons: workforce shortage, weak health care systems, and decreasing funding for research and care, both domestically and globally. In the aftermath of the November 2016 election, the proposed dismantlement of the Affordable Care Act could potentially threaten the historic clinical and public health gains that have been achieved in combatting the HIV/AIDS epidemic.

To conclude, the history of HIV/AIDS pandemic illustrates an unprecedented and heroic response that has successfully transformed the course of a devastating disease. In our roles as physicians and community members, we have been privileged to be involved in shaping the response to the AIDS epidemic in New Haven over the past 35 years. We have learned that despite historical and ongoing tensions between multiple stakeholders, it is the establishment and cultivation of multidisciplinary partnerships, such as those that have grown between YNHH, YSM, Yale School of Public Health, the City of New Haven, the CT DPH, and multiple community organizations, that truly result in high quality care.

Why do these partnerships work? We believe that no one individual or organization has the sole valid perspective on managing a disease as complicated as HIV/AIDS. Diverse approaches rendered in an open, ever evolving, and thoughtful manner are enriching for patients and providers alike. Based on our experience, we strongly believe that the example of the AIDS response can serve as a model for other chronic diseases that are challenged with implementing accessible, feasible, responsible and humane solutions to improving health outcomes.

1. Key members of this multidisciplinary group included physicians: John Dwyer (first MD director, Immunology); Warren Andiman (pediatrician); William Greene, Richard D'Aquila (ID); Frank Bia (ID); Peter McPhedran (Hematology); Lloyd Friedman, Andy Filderman, John Rankin (Pulmonary); John Booss (Neurology). Nurses included Sally Rinaldi (RN Coordinator), Ann Williams, and Letha Fraulino; Social Worker June Holmes.
2. Other key physician members recruited through the years have included: Peter Selwyn, Frederick Altice, Nancy Angoff, John Booss, Michael Rigsby, Helena Brett-Smith, Elizabeth Cooney, Michael Kozal, Krystn Wagner, Anne Fisher, Lynn Fiellin, Ben Doolittle, Lydia Chwastiak, John Francis, Douglas Bruce, Sandra Springer, Jaimie Meyer, Lydia Barakat, Sheela Shenoi, Onyema Ogbuagu, Dana Dunne, Margaret Fikrig, Brinda Emu, Serena Spudich, Jennifer Edelman. Other providers included Steven Farber (PA), Timothy Hatcher (PA), Julie Womack (APRN), Beverly Belton (RN), Wynnett Stewart (RN), June Holmes (MSW), Ann Murphy (MSW), Heidi Sorenson (MSW).