1983-2008
New York State Department of Health
AIDS
INSTITUTE
25 years

The New York State Department of Health AIDS Institute

July 30, 1983–July 30, 2008:

25 Years of Leadership, Service and Compassion

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AIDS Institute
New York State Department of Health
Albany, New York

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Message From the Director
Humberto Cruz

I remember the beginning of the HIV/AIDS epidemic. In 1983, when the AIDS Institute was created, I was the Director of Human Resources Development at a community-based organization in the Bronx. The months and years that followed brought many challenges. We lost friends, family members and loved ones, but we never lost hope that one day we might conquer this disease. The AIDS Institute has always been a critical player in the war against this terrible disease. I never dreamed that I would come to work at this incredible place and, one day, become its Director.

For many years, the idea of capturing the history of the AIDS Institute has been a dream of mine. In October 2007, in anticipation of the 25th anniversary of the creation of the AIDS Institute, an opportunity to make it a reality appeared. This document, which took more than two years to develop, chronicles the first 25 years of the AIDS Institute.

Preserving the AIDS Institute's evolution, and documenting the models that it has developed, are important for future generations and may be useful for unknown challenges to come. This chronology provides just a glimpse of what the AIDS Institute, as a government institution, has been able to accomplish. By itself, this chronology is not a complete picture. Together with other documents, such as reports and staff publications, the story of the public health campaign against HIV/AIDS in New York State, the epicenter of the domestic epidemic in the United States, is being told.

The AIDS Institute has grown and developed throughout its first 25 years in order to deal with the emerging epidemic. Methods and strategies used to pursue its mission have continually evolved. The AIDS Institute's history to date, and its accomplishments, reflect a remarkable trajectory of program and policy development. How is this possible? Staff members from diverse backgrounds and disciplines have brought an array of skills, perspectives and approaches to the challenges at hand. For years we faced many challenges and persevered. We worked side by side with: the community; service providers; persons living with HIV/AIDS; and many others.

Global threats and concerns have, at times, overshadowed the HIV/AIDS pandemic yet our unwavering commitment to our mission has never dimmed. For this, I want to thank each and every AIDS Institute employee, past and present, who has participated in the events chronicled herein for their leadership, dedication, compassion and commitment.

This document is dedicated to those who have lost their lives and to those who have tried to make a difference. Together we stand, together we fight, together we conquer.

Humberto Cruz
Director, AIDS Institute
May 2010

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Glossary of Acronyms

ACOG	American College of Obstetricians and Gynecologists
ACS	New York City Administration for Children's Services
ACT	Anonymous Counseling and Testing Program
ACT	Assets Coming Together for Youth Initiative
ADAP	AIDS Drug Assistance Program
AIDS	Acquired Immunodeficiency Syndrome
AIMS	AIDS Intervention Management System
AIRS	AIDS Institute Reporting System
APG	Ambulatory Patient Group
APIC	ADAP Plus Insurance Continuation Program
ARV	Antiretroviral
ASTHO	Alliance of State and Territorial Health Officers
AVHPC	Adult Viral Hepatitis Prevention Coordinator
AZT	Azidothymidine
CAPC	Community Action for Prenatal Care Initiative
CARE	Comprehensive AIDS Resource Emergency
CBO	Community-Based Organization
CCF	New York State Council on Children and Families
CCH	NYSDOH Center for Community Health
CD4	Cluster of Differentiation Four
CDC	U.S. Centers for Disease Control and Prevention
CDI	Community Development Initiative
CFP	Community Follow-up Program
CJI	AIDS Institute, Criminal Justice Initiative
CMS	Contract Management System
COBRA	Consolidated Omnibus Budget Reconciliation Act
CSP	Community Service Program
CTRPN	Counseling, Testing, Referral and Partner Notification
DAC	Designated AIDS Center
DOB	New York State Division of the Budget
DOCS	New York State Department of Correctional Services
DSS	New York State Department of Social Services
EHR	Electronic Health Record
EIIS	Early Identification and Intervention Services
ELISA	Enzyme-Linked Immunosorbent Assay
ESAP	New York State Expanded Syringe Access Program
FDA	U.S. Food and Drug Administration
FMAD	Families Making a Difference
GMHC	Gay Men's Health Crisis, Inc.
GRASP	Governmental Relations and Strategic Planning

GRID	Gay-Related Immunodeficiency
HCFA	Health Care Financing Administration
HCV	Hepatitis C Virus
HHS	U.S. Department of Health and Human Services
HIE	Health Information Exchange
HISPC	NYSDOH Health Information Security and Privacy Collaborative
HIV	Human Immunodeficiency Virus
HIV EFP	HIV Enhanced Fees for Physicians
HIVQUAL	National HIV Quality Improvement Project
HMO	Health Maintenance Organization
HRA	Human Resources Administration
HRSA	U.S. Health Resources and Services Administration
HTLV-III	Human T-Lymphotropic Virus Type IIII
ATF	New York State Interagency Task Force on HIV/AIDS
IDU	Injection Drug User
KS	Kaposi's Sarcoma
LTI	AIDS Institute, Leadership Training Institute
MMC	Montefiore Medical Center
MPHPCP	Maternal-Pediatric HIV Prevention and Care Program
MSA	Multiple Service Agency
MSM	Men Who Have Sex with Men
MTCT	Mother-to-Child HIV Transmission
NASTAD	National Alliance of State and Territorial AIDS Directors
NQC	National Quality Center
NYC	New York City
NYCDOHMH	New York City Department of Health and Mental Hygiene
NYS	New York State
NYSDOH	New York State Department of Health
OASAS	New York State Office of Alcoholism and Substance Abuse Services
OB	Obstetrical
OCFS	New York State Office of Children and Family Services
OMD	Office of the Medical Director
OMH	New York State Office of Mental Health
OMRDD	New York State Office of Mental Retardation and Developmental Disabilities
OPH	NYSDOH Office of Public Health
OTDA	Office of Temporary and Disability Assistance
PAFCC	Pediatric, Adolescent, Family Comprehensive Care
PCP	Pneumocystis carinii pneumonia
PCR	Polymerase Chain Reaction
PHL	Public Health Law
PLWHA	Persons Living with HIV/AIDS
PPG	New York State HIV Prevention Planning Group

PreCARE	Prenatal Care Provider Training Project
PSA	Public Service Announcement
QI	Quality Improvement
RFA	Request for Applications
RFP	Request for Proposals
RWCA	Ryan White CARE Act
SASDC	Statewide AIDS Service Delivery Consortium
SBTC	New York State Board Training Consortium
SED	New York State Education Department
SEP	Syringe Exchange Program
SNPHIV	Special Needs Plan
SOFA	New York State Office for the Aging
SPNS	Special Projects of National Significance
STD	Sexually Transmitted Disease
TB	Tuberculosis
TCM	Transitional Case Management
URS	Uniform Reporting System
WAVE	Project War Against the Virus Escalating
YD	Youth Development
YMS	Young Men's Study
ZDV	Zidovudine

Dedication

To the past, present and future staff of the New York State Department of Health AIDS Institute for all that the AIDS Institute has accomplished and for the foundation that has been laid for the future and to persons living with HIV/AIDS in the community and on staff for their insight, courage and persistence in helping build New York State's HIV/AIDS service delivery continuum.

Special thanks to Dr. Nicholas Rango, for his visionary leadership during his years as Director of the AIDS Institute. He set national standards for what a government response for this epidemic needs to be and promulgated and institutionalized a working collaborative effort between government and community. He was one of the casualties of this disease; his work and dedication continues to inspire all of us.

Dr. Nicholas Rango

Acknowledgments

This overview of the first 25 years of the New York State Department of Health AIDS Institute represents the collaborative efforts of a great many individuals and organizations. In particular, the accomplishments described herein would not have been possible without the dedication and expertise of the staff of the AIDS Institute, past and present. Staff members at all levels have contributed to the remarkable trajectory of program and policy development summarized in this chronology. Staff continue to support, develop and adapt programs and services for New York State's diverse population, doing so in a rapidly changing environment and often overcoming what many might view as insurmountable obstacles.

In responding to the HIV/AIDS epidemic, the Department and the AIDS Institute benefitted greatly from strong and visionary leaders. These have included New York State's Governors, Legislators and legislative staff, Commissioners of Health, Chairpersons and members of the AIDS Advisory Council and the HIV Prevention Planning Group and others. Within the AIDS Institute, the AIDS Institute Directors; Medical Directors; Executive Deputy Directors; Office, Division, Bureau and Section Directors and staff at all levels in all regions of the state have worked tirelessly to develop the continuum of HIV/AIDS prevention, care and supportive services that is a model for other states and nations. Other Health Department staff from a variety of programs have also contributed to the state's response, as have staff of Health Research, Incorporated and staff of various federal, state and local government agencies.

Leadership in the fight against HIV/AIDS in New York State has also come from health and human services providers and community members. Even prior to establishment of the AIDS Institute, the Department's response was guided by early efforts of activists and local providers. Over the years, the AIDS Institute and its partners developed a statewide infrastructure that relies upon community providers, government agencies and other organizations. Throughout its first 25 years, the AIDS Institute has emphasized, sought and supported community and consumer consultation and input. Individuals and organizations continue to generously share their knowledge, expertise and perspectives.

Special thanks go to those who made important contributions to this document by describing events, by providing background materials and by reading and providing comments on drafts. Their encouragement and support are gratefully acknowledged.

Preface

This chronological history of the AIDS Institute was prepared in conjunction with the 25-year commemoration of the creation of the AIDS Institute. It includes a brief history of the beginning of the HIV/AIDS epidemic in New York State (NYS), starting in 1981, to provide a context and it describes events leading to the creation of the AIDS Institute in 1983. The history is organized in five-year segments.

While this document does not contain a complete history of every program or initiative, it includes examples of evolution of some AIDS Institute programs over time. Current information and additional details about AIDS Institute programs and services are presented in "About the AIDS Institute," which is available on the NYS Department of Health (NYSDOH) web site. References to AIDS Institute reports and staff-authored publications are provided for use by those interested in accessing greater detail on specific issues or initiatives.

Introduction

> "AIDS is the major health challenge of this century. It is a life-threatening disease for which there is still no cure, no vaccine, no immediate symptoms to warn of infection, and no way to accurately predict how many people infected with the virus will become ill. Within this context, we must work to develop effective public policies to halt the spread of AIDS, and to prepare for its current and future impact on society."
>
> *– David Axelrod, M.D., New York State Commissioner of Health, before the Assembly Health Committee Public Hearing on Acquired Immune Deficiency Syndrome, February 19, 1987*

In June 1981, the United States (US) Centers for Disease Control and Prevention (CDC) published information about five young men who were being treated for *Pneumocystis carinii* pneumonia (PCP) in Los Angeles, California (CA).[1] One month later, on July 3, 1981, a *New York Times* headline "Rare Cancer Seen in 41 Homosexuals" anticipated publication of another report from CDC announcing diagnoses of Kaposi's sarcoma (KS) in 26 homosexual men, 20 of whom were in New York City (NYC) and six of whom were in CA.[2,3] Several individuals were found to have defects in their immune systems and sexual contact was hypothesized to be a risk factor. In August 1981, another article published in *The New York Times* described formation of a medical study group at CDC to further explore increasing numbers of reported cases of PCP and KS among homosexual men.[4] By May 1982, even though the cause of the disorder was unknown, researchers had begun to call it A.I.D. for acquired immunodeficiency disease, or GRID, for gay-related immunodeficiency.[5] The term "AIDS," for acquired immunodeficiency syndrome, was coined by the CDC in 1982.[6]

Recognition of the emerging epidemic was gradual in NYS, as elsewhere. Individuals and groups, particularly gay men, organized for mutual support and to seek help. In 1982, the Gay Men's Health Crisis, Inc. (GMHC), the nation's first HIV/AIDS community-based organization, was established in NYC, having evolved from an informal meeting of concerned members of the gay community held one year earlier in writer Larry Kramer's apartment in NYC.[6,7] Members of the gay community elsewhere in NYS became involved in grassroots efforts to address the epidemic as it began to spread. These grassroots efforts preceded an organized governmental response. Many local groups eventually received financial support from the AIDS Institute and provided insights that were used by the AIDS Institute for program planning and development.

With remarkable foresight, in 1983 the AIDS Institute was created within the NYSDOH to coordinate the state's policies and response to the growing epidemic. As one of the first efforts of NYS government to deal with the AIDS crisis, the creation of the AIDS Institute provided the organizational public health infrastructure and mission needed for an effective response. In its 25-year history, the AIDS Institute has provided leadership in NYS, at the national level and internationally. To this day, the AIDS Institute places a priority on community input, from persons infected and affected by the HIV/AIDS epidemic and from providers, to inform the development of programs and policies in NYS. Several mechanisms for community and provider input have been used over the years. These included statewide HIV/AIDS policy conferences, consumer and provider forums and advisory bodies. Working with others, the AIDS Institute has responded to myriad program and policy challenges. In response, it developed the concept of a comprehensive continuum of prevention, care and supportive services. The continuum that was developed in NYS has served as a model for other states and for other countries.

Since the very beginning of the epidemic, the NYSDOH and the AIDS Institute used a combination of traditional public health tools as well as new, and sometimes radical, approaches to address the challenges brought about by the HIV/AIDS epidemic. This maximized the potential for success. Many of the new approaches have found their way into other areas of public health practice. Hallmarks of the AIDS Institute's approach have included:

- Focus on mission and commitment to human rights.
- Partnerships with the community, with both consumers and providers.
- Recognizing and responding to the needs of all populations.
- Addressing psychosocial and other needs, in addition to medical needs.
- Innovative program models supported by Medicaid reimbursement.
- Coordination of primary and secondary prevention strategies.
- Evolution of a continuum of care and services based on changing needs, epidemiologic and other data, medical and scientific advances, co-morbidities, new treatments, etc.
- Strategic and equitable allocation of resources.
- High standards of care through program guidance, clinical guidelines, quality improvement program, rigorous contract monitoring and regulatory oversight.
- Leadership responsive to requirements of the times.
- Dedicated, experienced and knowledgeable staff with personal and professional commitment to fighting the epidemic.
- Keeping HIV/AIDS issues "on the table" (e.g., via events, media, advisory bodies).
- Advocacy for HIV/AIDS program and policy issues within the NYSDOH.
- Policy leadership and fostering of interagency and intergovernmental coordination and collaboration.
- Forging public and private developmental partnerships and collaborations to advance priority goals and objectives.
- Development of best practices and model public health policies.

Extraordinary program and policy changes accompanied the AIDS Institute's first 25 years. These are chronicled below.

1983-1987
Early NYS Response, Including Creation of the AIDS Institute

This section describes NYS' initial response to the emerging HIV/AIDS epidemic. Prominent features included:

- *Development of a NYS infrastructure, including an Executive Order to establish the Interagency Task Force to mobilize NYS government agencies, and enactment of Article 27-E of the NYS Public Health Law to create the AIDS Institute, as a focus of coordination of programs and policies, and the AIDS Advisory Council and AIDS Research Council.*
- *Community engagement, initially through Gay Men's Health Crisis, followed by funding of community-based providers serving identified populations, creation of community service programs in every region and co-location of prevention and substance abuse services.*
- *Inauguration of prevention education, anti-discrimination efforts and HIV counseling and testing services.*
- *Advent of programs and services to support access to azidothymidine (now called zidovudine or ZDV), the first antiretroviral drug that offered hope to many.*
- *Building organized structure and leadership for medical care via such initiatives as the Medical Care Criteria Committee, Designated AIDS Centers, information systems for monitoring care, clinical guidelines and creation of the AIDS Drug Assistance Program.*

1983 By January 7, 1983, all of the major routes of transmission had been identified and reported by the CDC.[1-5, 8-11] Transfusion-associated infections, and infections among children, led to heightened public concern. As the epidemic advanced, fear, ignorance, prejudice, homophobia, cultural stereotypes and racism were pervasive and stigmatized not only those who were infected but also those who were believed to be infected, most specifically members of groups identified by the CDC as being at highest risk: homosexual men, Haitians, intravenous drug users and hemophiliacs. Among the consequences were: social isolation; discrimination; loss of employment; prohibitions against blood donation; denial of medical care; and lack of access to services.
In NYS, as elsewhere, the health care and public health systems were challenged to respond to an epidemic with many unknowns and to a growing number of social issues that were not addressed by current policies.

Within the NYSDOH, Commissioner of Health Dr. David Axelrod was directly involved in the early response to the emerging epidemic. Dr. Axelrod relied heavily on staff from the Wadsworth Center, including the Director, Dr. Herbert W. Dickerman. One of the first issues to be confronted by NYSDOH was the matter of what steps, if any, should be taken to protect the blood supply.
On February 16, 1983, Wadsworth Center staff and members of the NYS Council on Human Blood and Transfusions Services, an advisory body to the Department on matters related to blood services, convened a Task Force on AIDS to advise the Council and the Department on recommended actions for dealing with AIDS, including the potential impact of AIDS on blood transfusion in NYS.

A few months later, on May 16, 1983, NYS Governor Mario M. Cuomo signed Executive Order #15 establishing an Interagency Task Force on AIDS. The Task Force was chaired by Commissioner

Axelrod and included representatives of the following NYS government agencies: Departments of Social Services, Department of Correctional Services, Commission of Correction, Department of Insurance, Division of Substance Abuse Services, Division for Youth and Office of Mental Health. The Task Force provided an initial report to the Governor on June 23, 1983, which included recommendations for governmental action in four areas: civil rights, education, treatment, and research.

In May 1983, Senator Roy Goodman, whose district was home to many politically active gay men, developed a legislative proposal (S5930), in response to the AIDS crisis. To address the urgency that more needed to be known about AIDS, Senator Goodman's bill would have created a research agency outside of the NYSDOH, with $4.5 million in research funds.

On June 1, 1983, Senator Goodman, who was Chairman of the Senate Committee on Investigation and Taxation, held a "Public Hearing on the State Role in Combating AIDS and Consideration of Pending Legislation."[12] Among the witnesses who testified were researchers; Mr. Michael Callen, diagnosed as immune deficient in 1982; Dr. Axelrod; and Dr. James F. Mohn, Chairman of the NYS Council on Human Blood and Transfusions Services. Issues discussed by Mr. Callen included scientific knowledge and gaps in knowledge, the importance of confidentiality, stigma and the need for public education. Dr. Mohn discussed the Council on Human Blood and Transfusion Services' AIDS Task Force, described a number of issues related to protection of the blood supply and, when asked directly, said that he would support S5930.

Dr. Axelrod discussed two guiding principles: "The first is dealing with public health issues as they really are, not as they are perceived to be or as they are perceived by other governmental agencies. The other is that we are to respect the civil rights of everyone involved."[12, p. 52-53] Dr. Axelrod discussed the Department's formation of the Interagency Task Force on AIDS; the then current clinical understanding of AIDS; the civil rights issues; the Department's provision of state funding to GMHC in early 1983 for prevention education; issues related to protection of the blood supply; and the need for research. Dr. Axelrod also implored state and national legislators to support research, adding that the state and the national government needed to do more. When asked whether or not he would recommend to the Governor that he sign Senator Goodman's bill, should it pass both houses of the NYS Legislature, Commissioner Axelrod said, "Yes."[12, p. 104] He later expressed an expectation that the senators "…would accept some specific recommendations for structural changes…"[12, p. 125] to the bill.

Recognizing the seriousness of the AIDS epidemic, the NYS Legislature passed legislation, sponsored by Senator Goodman, to create the AIDS Institute. The Legislature noted that:

> The medical resources of governments at the federal, state and local level have not yet been effectively marshaled to fight this epidemic.… The federal government must shoulder the largest burden of costs in the research and eventual elimination of this dread condition. However the state of New York within resources that realistically can be made available can make an important contribution.… It is imperative that steps be taken towards establishing a comprehensive program to combat acquired immunodeficiency syndrome (AIDS) to be implemented through the combined correlated efforts of state and local governments, medicine, universities, nonprofit organizations and individuals.[13, p. 123-124]

Governor Cuomo signed Chapter 823 of the Laws of 1983 into law amending the NYS Public Health Law by adding a new Article 27-E, effective July 30, 1983. Article 27E established the AIDS Institute within the NYSDOH. Section 2775 gave the AIDS Institute "the central responsibility

for. . . coordinating the state's policies with respect to acquired immune deficiency syndrome."[13, p. 122] The AIDS Institute was given specific powers and duties, set forth in Section 2776, as follows:

(a) to develop and promote scientific investigations into the cause, prevention, methods of treatment, and cure of the acquired diseases of immunosuppression;

(b) to develop and promote programs of professional education and training and improvements in instrumentation as necessary adjuncts to such scientific investigations;

(c) to develop and maintain a clearing house within the department for information collected on acquired immune deficiency syndrome, including a catalogue of the existing medical literature and the results of existing epidemiological studies;

(d) to develop and promote an outreach campaign directed toward targeted high risk populations to provide coordinated information regarding the treatment and counseling programs and sources of financial assistance available; and

(e) to promote the availability of supportive services for affected persons.[11, p. 124-125]

The decision to create the AIDS Institute within the Department, rather than as an independent entity, was accompanied by agreement to create two advisory bodies. The first was defined by new Public Health Law Section 2777 as a seven-member AIDS Research Council, whose members would be appointed by the Commissioner, to advise the Commissioner with respect to certain AIDS Institute activities.[13, p.125-126] The second was an AIDS Advisory Council, whose members would be appointed by the Governor and the Legislature. The AIDS Advisory Council, defined by Public Health Law Section 2778, was charged with advising the Commissioner with respect to implementation of Public Health Law provisions defining the AIDS Institute.[13, p. 126] The AIDS Advisory Council has contended with a wide range of program and policy challenges, providing leadership and recommendations for action.[14] The initial budget for HIV/AIDS activities, providing funds for research and services for persons with AIDS, was $5.25 million. NYS was the first state to allocate funds for AIDS research.

In September 1983, Dr. Axelrod appointed Melvin L. Rosen as the AIDS Institute's first Director. From 1983 to 1987, Mr. Rosen, known as Mel, served as the first Director of the AIDS Institute, commuting back and forth from the AIDS Institute's office in NYC, where some other early AIDS Institute staff members were also stationed, to the Department's main office in Albany, where he had ready access to Dr. Axelrod and other senior staff.

Three staff members were hired immediately, with additional staff hired over the years, as provided by successive NYS budget appropriations and federal grants. Some staff members were recruited from the community, initially including many from the gay community and, later, individuals from other populations and backgrounds with direct experience with the epidemic. Others joined the AIDS Institute from within the Health Department. For many, the fight against the epidemic has been a personal and/or professional mission. Over the years, AIDS Institute staff members have dedicated their expertise, skills and hard work to developing a comprehensive HIV/AIDS program, often working long hours not because they had to but because they were motivated to combat the epidemic and save lives. Twenty five years later, the AIDS Institute had grown to include more than 400 staff members and to oversee more than $442,590,680 in state and federal funds, and more than $2 billion in Medicaid expenditures for patients with HIV/AIDS. Despite its size, the AIDS Institute has maintained an organizational culture that emphasizes: compassion; community empowerment; eradication of stigma and discrimination; and elimination of health disparities.

The AIDS Institute began to develop the concept of regional task forces, which later became known as Community Service Programs (CSPs). In 1983 the NYS Legislature first appropriated funds specifically to support the work of a task force in each region of the State. GMHC was the first community-based organization to receive NYS funding for outreach, education and supportive services. AIDS Institute staff traveled throughout the state to facilitate the development of CSPs to provide these same services in other regions, using GMHC as a model. In 1984, four CSP(s) were established. Over time, the AIDS Institute developed a statewide network of 14 CSPs as a prominent feature of NYS' response to the epidemic. By 1990, this network was complete. It has remained intact since 1990.

The CSPs have grown over the years through supplemental NYS appropriations and by their ability to qualify for or attract additional funding from both the public and private sectors. The CSPs offer a standard model across regions, such that someone from one region can go to another region and receive a consistent array of services. Other health and human service providers are familiar with and refer clients to CSPs and CSPs make referrals to other providers, as appropriate. Over the years, the CSPs adapted to the changing nature of the epidemic. For example, many now have syringe access and/or safe disposal initiatives. The CSPs fulfill broad regional roles, offering comprehensive primary and secondary prevention and supportive services to individuals. The CSPs also conduct and/or participate in community health activities, such as needs assessments and regional planning for both prevention and care.

1984 As the AIDS Institute began to take shape, Wadsworth Center staff continued an active role. They oriented and worked closely with new AIDS Institute staff and they organized and convened the AIDS Research Council to award funds for research.[15-16] Twenty-eight two-year grants totaling $5.1 million were awarded in 1984. Emphasis was given to the funding of proposals that complemented the federal program of AIDS research. Funded projects included basic science, clinical and epidemiologic studies. The AIDS Advisory Council was also developed and initial appointments were made. Senator Goodman appointed himself. Other appointees included Episcopal Bishop Paul Moore from NYC, who served from 1983-1987 as the first Chair of the AIDS Advisory Council. Subsequent Council Chairs were Dr. David E. Rogers (Chair, 1987-1994), Dr. Allan Rosenfield (Chair, 1995-2005) and Sandra Ruiz Butter (Chair, 2005-present). The AIDS Advisory Council held its first meeting in early 1984. The AIDS Institute, the AIDS Advisory Council and the Department were immediately confronted with numerous issues raised by lack of knowledge about AIDS, fear and homophobia.

A team of scientists and doctors in France, led by Dr. Luc Montagnier, had isolated the virus that was ultimately proven to cause AIDS in 1983. The following year, the virus, renamed as HTLV-III, was isolated and grown by Dr. Robert Gallo from the National Cancer Institute, who reported that it had been determined to be the cause of AIDS.[17] In March, blood banks in NYS were encouraged to begin screening donated blood using the ELISA test.

1985 Screening of donated blood was required in NYS effective May 15, 1985. An April 23, 1985 press conference organized by Margaret Heckler, Secretary of Health and Human Services (HHS), announced awards to drug and biotechnology companies to develop an HTLV-III test kit.[18] The Wadsworth Center submitted a proposal to the CDC and received funding (Cooperative Agreement No. 062/CCU200873-01) to support development of a statewide network of "Alternate Sites to Blood Donation Facilities" to provide individuals seeking testing an option other than blood banks. In the spring of 1985, the laboratory testing and counseling components of the NYS alternate site program were established. In order to ensure a timely turnaround of specimens from various locations throughout NYS, a structure utilizing the Wadsworth Center and affiliate laboratories

was established. On July 8, 1985, a letter from Dr. Axelrod provided guidance to health care providers on HTLV-III antibody testing, including how to access laboratory services.

In 1985 the FDA approved the first antibody test for HIV. Shortly thereafter, staff from the AIDS Institute's Education and Training Unit developed and delivered training programs to prepare providers to offer HIV testing. In the mid-1980s, no other public, private, health care or academic entity had the capacity to offer statewide training on HIV/AIDS testing. The Overview of HIV/AIDS (one day) and the HIV Test Counselor training (3 days) were offered throughout NYS by staff from the Unit. Later, with the passage of Article 27-F in 1988, these trainings were updated to include the requirements of HIV testing and confidentiality outlined in the Public Health Law. From 1987-1992, staff from the Education and Training unit trained approximately 5,000 health and human services providers annually.

Inauguration of HIV counseling and testing services in early 1985 was timely. Rock Hudson's AIDS diagnosis became public knowledge shortly afterwards. The publicity around that diagnosis resulted in hotline calls from individuals wanting information about the disease and, in some cases, seeking guidance about where they could be tested.[19-20] For many, Mr. Hudson was the first person they knew who had AIDS. Six years later, the news that Los Angeles Laker, Earvin "Magic" Johnson, was retiring as a result of his HIV infection caused a similar surge in testing, including in NYS.[21-22] Mr. Johnson subsequently used his celebrity to advance HIV/AIDS education and testing, particularly in African-American/Black communities.[23]

Another, less famous, individual became a household name in 1985. Fourteen-year-old Ryan White, who had contracted HIV through blood-based products used to treat his hemophilia, was barred from attending school in Kokomo, Indiana, due to his illness. Publicity about his fight to attend school and live a normal life drew public sympathy and attention to the discrimination faced by persons with HIV/AIDS. Celebrities and other public figures, including Michael Jackson, Elton John, Greg Louganis and Donald Trump reached out to him. Ryan White became a hero for many. As noted below, Ryan White died of AIDS in 1990 at age 18.[24] The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, a national program that funds services for people with HIV/AIDS, was named in his honor.

In a press conference on October 24, 1985 to announce an AIDS education campaign, Governor Cuomo said "Until the scientists find a cure for AIDS, education is our only vaccine."[25] Packages of materials, which were distributed widely, included the Governor's Press Release, an AIDS Institute publication entitled "100 Questions and Answers About AIDS," epidemiological data, a letter from Commissioner Axelrod and four reports. The reports summarized educational and support services, state-funded research projects, criminal justice policies and future initiatives.

During 1983-1987, the NYSDOH made a series of decisions to develop and fund specific administrative structures and targeted program initiatives to intervene in the spread of AIDS. Over time, the concept of a comprehensive continuum of HIV/AIDS prevention, care and supportive services (Figure 1) became a reality in NYS. This continuum supported integration of primary and secondary prevention for persons living with HIV/AIDS long before integration of prevention and care and "prevention with positives" were emphasized as essential elements of the national response to HIV/AIDS.[26-27] The continuum supported targeted health care service extending from primary to long term care.

In 1985, the NYSDOH adopted emergency regulations to implement hospital-based AIDS centers. Most, but not all, would be located in NYC, with those in major upstate urban areas providing regional coverage.[28] The Designated AIDS Center (DAC) hospitals were charged with providing a

comprehensive, multidisciplinary team approach to care through the coordination of an array of services ranging from inpatient, ambulatory and long-term care to psychosocial support. DACs were a precursor to the national medical home initiative. DACs were responsible for implementing 13 standards of care for persons with HIV/AIDS. The DAC program was part of the Department's strategy for ensuring that hospitals would provide care responsive to the needs of persons living with HIV/AIDS in an era when even some medical providers stigmatized these patients. The DAC program helped define what constituted quality AIDS care. It also served to direct people to centers of expertise at a time when clinical knowledge was minimal and experienced providers few. By leveraging both enhanced inpatient and outpatient Medicaid reimbursement, the AIDS Institute was able to support the programmatic development of multidisciplinary care and hospital-based case management. The inpatient per diem reimbursement rates for the DACs, begun in 1986, were 40-50% higher than standard hospital per diem rates. A seven-tier outpatient rate established at the same time provided for comprehensive outpatient care.

1986 On May 28-30, 1986, "AIDS Impact on Public Policy, An International Forum: Policy, Politics and AIDS" convened at the New York Hilton at Rockefeller Center. Cosponsored by the NYSDOH and the Milbank Memorial Fund, the Forum brought together social scientists, researchers, clinicians, educators, community leaders, government officials and public policy analysts who were involved with AIDS on a national and international level to explore and discuss major AIDS public policy issues. The range of issues discussed and debated included: syringe exchange; treatment; impact on the health care system; AIDS and economics; international cooperation; competition in research; public health; and human rights.[29] In his introductory remarks, Dr. Axelrod pointed out that:

> The devastating effect of AIDS, its severity, its impact on at-risk populations, the fears that it has generated in the general populace, have created an enormous challenge to our political structure, to medical science and to our health institutes and social agencies. Our public/private health partnership is being stressed to an uncommon degree. To government, AIDS heralds the onset of vastly more complex viral diseases than any we have encountered before. To the human species, AIDS is the latest chapter in mankind's eternal struggle with infectious organisms, a struggle which some thought was over.[29, p. 2]

During the panel session on Clinical Management: Treatment Modes and Impact on the Health Care System, Dr. Axelrod commented that:

> In the absence of a vaccine and the absence of effective therapies, states like New York have a responsibility for governmental initiatives that demonstrate their social responsiveness, their concern, and their ability to provide for those who are afflicted with the disease.... New York State, as part of its response, has established an AIDS Institute that assumes all of the responsibilities for coordinating services, educational and preventive activities.[29, p. 77]

The AIDS Institute needed to develop the capacity to provide leadership to promote, monitor and support the quality of clinical services for people with HIV/AIDS. In 1986 a Medical Director was appointed within the AIDS Institute and, to date, the AIDS Institute has had five Medical Directors. From 1986-1988, Dr. Judith Simmons served as the first Medical Director, offering clinical advice during the early days of the epidemic and helping to build the foundation for NYS' AIDS Drug Assistance Program. She was succeeded by Dr. Helen Rodriguez-Trias, a champion for the rights and health of women and their children, who helped to highlight the impact of HIV on these populations in NYS and across the nation. Dr. Gary Burke, who served as a medical consultant to the AIDS Institute, was Medical Director from 1989-1992, during which time the first clinical

guidelines for care of children and adolescents with HIV infection were published.[30] He contributed to the design of the comprehensive HIV primary care model, ensuring these programs were available in highly impacted, underserved areas, and developed working relationships with clinicians working on the front lines of the epidemic. Dr. Nilsa Gutierrez, who joined the AIDS Institute as a medical consultant in 1989 and served as Associate Medical Director, became Medical Director in 1992. She held this position until becoming the Director of the AIDS Institute in 1994. Dr. Gutierrez was instrumental in ensuring the continuum of HIV care and services was available statewide and emphasized the importance of recommending HIV testing to every woman during pregnancy for early access to treatment. In 1994, Dr. Bruce Agins, who had joined the Institute in 1990, became the Medical Director. Since 1994, Dr. Agins has overseen the Office of the Medical Director (OMD) and its HIV Quality of Care Program, guidelines development,[31] and educational programs.[32-33] Working collaboratively with HIV clinicians, he pioneered the development of specific quality of care indicators and the use of continuous quality improvement strategies[34-35] in HIV clinical settings which became a model for the nation.[36-37]

Also in 1986, the HIV Clinical Guidelines Program was launched. AIDS Institute clinical guidelines are developed by distinguished committees of clinicians and other experts with extensive experience providing care to people with HIV infection. Committees are charged with developing standards of care for patients in their areas of specialty. Committees meet regularly to assess current recommendations and to write and update guidelines in accordance with newly emerging clinical and research developments. External peer and consumer review of all new and revised guidelines ensures that opinion from outside the committees is incorporated. Since its inception, the HIV Clinical Guidelines Program has published more than 80 guidelines, as well as related materials. A clinical guideline published in 1998 was the first guideline developed specifically to promote integration of HIV prevention strategies in clinical medicine. Another, published in 2001, was the first ever (and is still the only) guideline addressing medical management of HIV infection among people with mental illness and mental illness among people with HIV infection. These and other guidelines are broadly accessed through an HIV Clinical Resource website jointly maintained by OMD and Johns Hopkins University Division of Infectious Diseases (www.hivguidelines.org).

In 1986, the AIDS Institute launched the AIDS Intervention Management System (AIMS) to collect, organize, and evaluate data associated with the care of HIV-infected patients. Today, AIMS is responsible for inpatient and outpatient utilization and quality of care reviews at DACs and ambulatory care facilities and for analysis and reporting of data gathered through all review activities and special studies. The initial concept for AIMS was an ambitious plan to create a longitudinal patient database. Over time, AIMS evolved as a tool to monitor quality and utilization.

With a statewide policy role, development of new models of care, often in collaboration with clinical providers in NYC, and a significant investment in programs and services, particularly in NYC, came an AIDS Institute leadership presence that extended statewide, including within NYC. When Dr. Stephen C. Joseph became Commissioner of Health in NYC in 1986, he had hopes to restore the City Health Department to "its former position of pre-eminence among health departments."[38] Dr. Joseph also chose the HIV/AIDS epidemic as a major focus of his attention, maintaining a highly visible role and serving as a catalyst to engage other NYC government agencies in the City's response.[39] Dr. Joseph's tenure marked a more active role on the part of the City Health Department. The AIDS Institute and the NYCDOHMH have a rich history of collaboration and staff members maintain regular communication.

An updated version of "100 Questions & Answers," released in November 1986, was widely distributed. "100 Questions & Answers" has been updated and re-released several times. It remains a mainstay of the AIDS Institute's educational materials.

1987 The AIDS Drug Assistance Program (ADAP) was established in 1987, the year that the US Food and Drug Administration approved AZT (azidothymidine, now called zidovudine or ZDV), as part of a national program to provide free HIV/AIDS drugs to low-income individuals not covered by Medicaid or adequate insurance. Implementation of ADAP was guided by a study that examined barriers to participation.[40] AZT was the first antiretroviral (ARV) drug to gain FDA approval when it was found to provide short-term benefit and prolong life in patients with advanced AIDS. AZT was later found to prevent mother-to-child transmission of HIV. As the first antiretroviral therapy available, AZT gave people hope. ADAP brought life-prolonging treatment to people who lacked financial or insurance resources to obtain it on their own.

On August 10, 1987, Governor Cuomo signed Executive Order #99, amending Executive Order #15 to expand the state agency membership of the Interagency Task Force on AIDS from eight to 14 agencies. Additional member agencies were: the Office of Mental Retardation and Developmental Disabilities; the Division of Human Rights; the Department of Labor; the Division for Women; the Division of Alcoholism and Alcohol Abuse; and the Office of Employee Relations. Governor Cuomo appointed his Deputy Secretary for Human Services as Chairperson. Governor Cuomo also sought agreement from the Legislature to expand the membership of the AIDS Advisory Council, and the Council's membership increased from four to seven members.

Dr. Axelrod initiated large scale seroprevalence studies during 1987 in order to effectively combat the HIV epidemic. "The seroprevalence studies. . . were undertaken to document the extent and trends of infection, the sociodemographic characteristics of the affected populations, and the risk factors that appear to explain the past and current spread of infection."[41. p. 7] The seroprevalence studies were referred to as "blinded," which meant that demographic data, but not identifying information, were available for review, leaving the researchers "blinded" from information that would reveal the identities of specific individuals. Data collection for epidemiologic studies of several populations (e.g., prison inmates, STD and family planning clinic clients, persons receiving substance abuse treatment) began in November 1987, with newborn seroprevalence data collection initiated November 30. Review of initial newborn seroprevalence data revealed rates of up to 4% among childbearing women in some NYC neighborhoods. The Department acted on this information quickly. Four weeks later, contracts with family planning and prenatal providers serving large numbers of women had been amended to require on-site HIV counseling and voluntary testing.[42] Epidemiological data have continued to guide the development of AIDS Institute programs and services.

1987 also saw the release of a coordinated statewide campaign titled, "AIDS Does Not Discriminate," launched on April 9, 1987, in coordination with other NYS government agencies (e.g., Division of Substance Abuse Services – now OASAS, and the Education Department). The campaign was in response to the ongoing stigma and discrimination faced by persons with, and at risk for, HIV/AIDS. It reinforced that all sectors of society have the same risk factors via a toll-free hotline; radio and television spots; transit ads; paycheck inserts; posters; and bilingual publications. The AIDS Institute continues efforts to reduce HIV/AIDS-related stigma and discrimination and works with others to address the multiple stigmas faced by many individuals and populations.[43] In addition, the AIDS Institute continues to support toll-free hotlines in both English and Spanish.

In 1987, for the first time, the number of reported AIDS cases among injection drug users surpassed the number of cases among men who have sex with men (MSM). As the extent of the epidemic among injection drug users increased, discussion turned to syringe exchange and drug treatment as a potential intervention.[44-45] On August 4, 1987, Governor Cuomo released "AIDS: New York's Response," providing an update on the status of the epidemic, reiterating NYS'

commitment to addressing the many challenges associated with HIV/AIDS, summarizing actions taken in NYS in several areas (e.g., services, research, education, counseling and testing) and committing additional state resources. He also directed the Division of Substance Abuse Services (now OASAS) to expand methadone maintenance treatment and related counseling services to drug users and their families.

Governor Cuomo expanded the membership of AIDS Advisory Council, adding three new members, all physicians, who brought expertise and experience in meeting the needs of substance users and other disenfranchised populations (e.g., homeless persons). Dr. David E. Rogers, who joined the Council at that time, served as its Chair until his death in 1994. Dr. Rogers believed that physicians should play an active role in government, including policymaking,[46] and he viewed AIDS in its larger societal context.[47-48] He played a very active role in HIV/AIDS policy in NYS and NYC (where he headed the Mayor's Task Force on AIDS), as well as nationally, (where he served as Vice Chair of the National Commission on AIDS).[49]

Across the country, public health leaders and state policy makers were trying to determine how best to approach the AIDS epidemic. To advance the discussion, The George Washington University's Intergovernmental Health Policy Project undertook a national study of programs, policies and initiatives adopted by the states. The findings, published in October 1987, highlighted several aspects of NYS' response, including:

> "The New York State AIDS Institute represents an innovative solution to a critical health problem. . . . Several elements have probably contributed to the success of New York's Institute: 1) it was created with a clear purpose and goals; 2) it has legislative, gubernatorial and strong financial support; 3) it combines policy-making authority with program responsibility; 4) it has developed decentralized systems, allowing it to directly fund an area's special needs; 5) it has developed strong intra-agency and community coordinating mechanisms; and 6) the executive leadership was involved with community AIDS organizing efforts.[50, p. 1-17]

In late 1987, Dr. Axelrod announced the appointment of Dr. Nicholas A. Rango, known to many as Nick, as Director of the AIDS Institute. With Dr. Rango's appointment, and in response to: the unwillingness of nursing homes to accept AIDS patients; the lack of necessary practices (e.g., infection control); inadequate staffing and concerns about intermingling HIV/AIDS patients with elderly nursing home residents; discussion of concepts for long-term care of patients with HIV/AIDS ensued.[51] Dr. Rango was an extremely intelligent, articulate and passionate leader of the AIDS Institute at a critical time in the course of the epidemic. He was well-known for being outspoken and for directly confronting any organization or individual whom he believed was not aggressively combating the growing epidemic. Dr. Rango served as Director of the AIDS Institute until his death in November 1993. During his tenure the AIDS Institute's budget quadrupled and, as described below, a wide variety of programs were put into place, making the AIDS Institute a model for the country. An interview published in *The New York Times* on June 13, 1993 provided insights into Dr. Rango's passion. In addition to disclosing his AIDS diagnosis, the article conveyed his impatience with progress made in the fight against AIDS, his respect for ACT UP (the AIDS Coalition to Unleash Power) as "the soul of AIDS advocacy" and his commitment to maximizing the critical role of the AIDS Institute. Dr. Rango was described as "the anti-bureaucrat, famous in Albany for his impatience and almost rude manner. . . . considered by advocates as the conscience of AIDS in New York."[52] HIV/AIDS program and policy development in NYS benefitted greatly from the active involvement of three powerful leaders – Drs. Axelrod, Rogers and Rango.

1988-1992
Extension of the AIDS Institute's Role and of the HIV/AIDS Service Delivery Continuum

This section discusses the continued response to HIV/AIDS in NYS. Of particular note during 1988-1992 were:

- *Enactment of Article 27-F of the NYS Public Health Law, often referred to as NYS' HIV/AIDS Confidentiality Law.*
- *Publication of a "Five-Year Interagency Plan" that set forth a template for concerted efforts of 18 NYS agencies.*
- *Integration of HIV/AIDS programs and services within primary care settings; provision for day care, home care and nursing home needs; greater attention to the need for a well-prepared clinical workforce and launch of ADAP Plus to help meet the needs of uninsured persons.*
- *Recognition of the need for additional prevention efforts for injection drug users via authorization of syringe exchange programs within a comprehensive harm reduction model.*
- *Engagement of additional community-based agencies and organizations as Multiple Service Agencies and Community Development Initiatives to meet the needs of specific communities of color and to advance community leadership and mobilization.*

1988 In January 1988, in his State of the State address, Governor Cuomo called for a five-year interagency plan to respond to the AIDS epidemic. This plan's development was to be coordinated by the AIDS Institute and would identify and focus attention on major HIV/AIDS issues and needs. The "Five-Year Interagency Plan," spearheaded by Dr. Rango, was widely anticipated as the blueprint for addressing the health care delivery system crisis as it pertained to HIV/AIDS. Similarly, it was hoped that the plan would lead to an increase in the state's programs and services through the efforts of NYS government agencies, working in partnership with others. The planning process also provided an opportunity for assessing and addressing policy issues. Even as the plan was being developed, many urged Governor Cuomo to issue an Executive Order to overrule local opposition to housing for persons with AIDS and to new sites for drug treatment programs.[53] The plan was developed through an intensive process, which included cooperative planning that involved 18 State agencies and consultation with more than 300 key individuals. The plan, distributed in January 1989, was titled "AIDS – New York's Response: A Five-Year Interagency Plan"[54] It contained more than 200 specific recommendations, constituting the state's strategy for halting the spread of HIV. It included a commitment to caring for HIV-infected individuals and to ongoing efforts to prevent discrimination against those at risk for AIDS. The plan predicted continued yearly increases in the AIDS caseload through 1994, with the need for an increase in services. The plan became NYS' blueprint for the next five years and beyond.

Early 1988 also saw the inauguration of a pilot program in NYC that provided injection drug users (IDUs) with clean, sterile syringes.[55] This pilot, proposed by the NYC Department of Health, which later became the NYC Department of Health and Mental Hygiene (NYCDOHMH), would provide syringe exchange services to one of two groups of 200 drug injectors awaiting entrance into drug treatment. Used syringes would be analyzed to assess the extent of syringe sharing and

individuals would be assessed for new HIV/AIDS infections. Objections included: the failure of the pilot to address risks of sharing of other injection equipment (e.g., cookers, cotton); perceptions that government was aiding addicts in continued use of illicit drugs; decline of neighborhood quality in areas where syringe exchange would occur; and concerns that an underlying issue of lack of adequate drug treatment slots in NYC was not addressed.[56] This controversial pilot opened on November 7, 1988 at only one site and was discontinued one year later, after the mayoral election in NYC in November 1989.[55]

Just as the AIDS epidemic revealed underlying issues associated with inadequacies of available drug treatment programs, issues regarding the state's health care delivery system were also underscored and exacerbated by the growing epidemic. By 1988, shortages of hospital beds, hospital workers and other necessary resources that were first felt in NYC began to be felt statewide.[57] The NYS AIDS Advisory Council, chaired at the time by Dr. David E. Rogers, formed a committee to look at the health care delivery systems issues, headed by Council member Dr. Bruce Vladek, President of the United Hospital Fund. To meet the needs of AIDS patients alone, the committee recommended the addition of 1,500 hospital beds and up to 500 nursing home beds dedicated to their needs by 1991.[58] Concerns about capacity continued to be voiced, including by Council members, especially in NYC. In response, the state and City health departments prioritized development of improved estimates of AIDS cases.[59-60] Meanwhile, AIDS among homeless persons in NYS, including IDUs, highlighted the need for housing options, for review of housing policies and for increased drug treatment capacity.[61]

In recognition of the impact of the epidemic on infants born to HIV positive mothers, in 1988 the NYS Legislature appropriated the first funds specifically targeted for comprehensive health care services for children with HIV. That year, two grants were awarded to the hospitals in NYC having the highest seroprevalence among childbearing women. Also in 1988, the Legislature appropriated funds to expand the number of grants to hospitals for pediatric/maternal HIV services, as well as grants for medical respite for families with HIV infected children and for specialized day care services for severely immunocompromised children. Prenatal and family planning clinics received funds to offer voluntary counseling with testing and referral to care.[62-64] Regulations for the DACs were expanded in 1988 to include a special focus on positive pregnant women and their children, inaugurating Pediatric Maternal HIV Services in DACs.

In response to the epidemic's increased rate of expansion in specific communities and the recognition of the need to support community involvement, including through funding local community-based agencies and organizations, in 1988 the AIDS Institute established a Community-Based Organization Initiative. Funding was provided to agencies and organizations that were an intrinsic, established part of the fabric of the community to reach communities and populations that were bearing the brunt of the emerging epidemic. Community-based organizations (CBOs) received support to provide a specific service or services (e.g., outreach; prevention education; peer education) to specific geographic communities (e.g., Harlem) or populations (e.g., Haitian/Caribbean women). Some CBOs also offered support groups for community members. AIDS Institute staff provided guidance and support to the CBOs and, in turn, gained valuable insights and understandings that further informed the AIDS Institute's work with CBOs. Eventually, guidance documents on topics such as peer education and support groups were jointly developed by AIDS Institute staff and individuals from CBOs.[65] These were made available to other agencies and organizations willing to offer such services but lacking direct experience, and sometimes led to new programmatic initiatives (e.g., Peer Model of Service Delivery). Not only did the AIDS Institute fund CBO-based peer programs, it also recruited staff

representative of affected communities for front line positions (e.g., recruited ex-offenders for its prison-based education, counseling and testing project) as well as management positions.

Also in response to the impact of the epidemic on women and children, in the fall of 1988 the AIDS Institute established a Criteria Committee for the Care of HIV-Infected Children. The Committee included pediatricians and other health care professionals from across NYS who were involved in caring for infants, children and adolescents with HIV/AIDS. Its role was to develop standards for medical care of children with HIV/AIDS. The Committee worked on clinical guidelines for approximately 18 months, meeting at Columbia University every other Friday afternoon. Clinicians often shared the details of individual patients that they were caring for during the meetings in the hope that others could offer advice and guidance. Often, the details of individual cases were unprecedented and there was no guidance to follow. Together, the participants formulated strategies, using the best available information.

The absence of alternative levels of care placed strains on acute care hospitals which did not have good discharge options for patients with symptomatic AIDS. Long-term care services for those individuals were essential and, in 1988, regulations were established for AIDS nursing facilities. The establishment of these facilities presented new challenges to the long-term care industry to provide more active and aggressive clinical and preventive interventions to non-geriatric populations most of whom had previous or active substance abuse and mental health treatment needs. A total of 1,079 beds were developed under the AIDS nursing home initiative. These facilities were financed using NYS bonds.

The year 1988 was also momentous in that sections of the NYS Public Health Law (PHL), the Insurance Law and the Social Services Law were amended with respect to HIV/AIDS, with changes to take effect on February 1, 1989. The amendments to the PHL created Article 27-F, generally known as the HIV/AIDS Confidentiality Law. Article 27-F reflected recognition, on the part of the NYS Legislature and the Governor, that adding confidentiality protections for information related to HIV/AIDS was essential to prevent improper disclosure of confidential information, to protect the privacy of persons at risk, to encourage individuals to come forth and be tested and to establish clear, specific rules for disclosure of information pertaining to HIV/AIDS. Article 27-F established the basic legal rules to govern confidentiality and disclosure of information about individuals who have sought HIV testing or have been diagnosed with HIV infection or related illnesses.

1989 Article 27-F was put into effect in 1989, with the AIDS Institute responsible for oversight and enforcement. This landmark legislation, which helped to encourage testing by ensuring confidentiality of HIV information and prescribing penalties for breaches, was a model for the nation and helped propel NYS to a national leadership position in the fight against HIV/AIDS stigma and discrimination.

As the epidemic expanded and evolved, policy issues continued to require attention. In the fall of 1989, a Policy Unit was established within the AIDS Institute. Working closely with Drs. Axelrod, Rango and Rogers, the Policy Unit provided a focus for work on policy issues. An immediate need was the development of regulations to implement Article 27-F and mechanisms to enforce the new law. The Unit also provided staff support for the AIDS Advisory Council and for committees of the Council that were formed to provide recommendations on such issues as management of HIV in the state's prison system, occupational exposure, prevention needs of adolescents and HIV-infected health care workers. The Unit also convened expert committees to help the AIDS Institute and the Department grapple with complex policy questions, such as testing issues and how best

to prevent mother-to-child transmission. Dr. Rango also led an AIDS Policy Committee within the NYSDOH that brought together senior executive level staff from the Office of Public Health and the Office of Health Systems Management to focus attention on program and policy issues which required discussion and development within the Department (e.g., using reimbursement to build health care system capacity for HIV/AIDS).

Throughout the 1980s, the issue of appropriate public health policies regarding the issues raised by HIV-infected health care professionals had been debated. The CDC and numerous professional and public health organizations sought to provide guidance, despite a lack of a consensus on the issues. The Department and the AIDS Institute were faced with numerous instances of employer responses, such as denial of employment and limitation of duties, to HIV-infected health care workers. In developing regulations to implement Article 27-F, the AIDS Institute and Department were also confronted with the need to define "significant risk" for acquisition and transmission of HIV in occupational settings. In NYS, a carefully crafted definition of "significant risk" that was included in regulations pursuant to Article 27-F does not restrict HIV-infected health care workers from patient care, including invasive procedures, when scientifically accepted infection control procedures are adhered to. Later, in 1990, when the CDC began to consider guidelines for mandatory testing of health care workers, the NYSDOH was the only public health department that took a position opposed to mandatory testing. The AIDS Institute went on record, in writing, to CDC in opposition to the proposed guidelines. Drs. Axelrod and Rogers, both highly respected national leaders, played prominent roles in the national debate.[66-67]

Another complex policy issue emerged during 1989. It focused on the standards of care for nursing homes for patients with AIDS, in particular, their applicability to nursing facilities run by the Roman Catholic Archdiocese of New York. The Archdiocese had responded with several projects in response to the need for nursing homes for persons with AIDS.[68] Standards of care for services for nursing home patients with AIDS, many of whom were much younger than the traditional nursing home population, included such components as prevention education, including about sexual risk; access to condoms; counseling regarding abortion (at the time, there were no known methods to prevent mother-to-child transmission); and pregnancy prevention/reproductive health care services. For religious reasons, Roman Catholic officials were unwilling to offer services such as promotion of condoms, safer sex and abortion counseling. The Archbishop maintained that the best prevention strategy was abstinence from sex and drugs and opposed providing condoms and teaching safer sex.[69-71] The standoff between the Department and the Archdiocese on this issue led to demonstrations against Cardinal O'Connor and the Catholic Church by the AIDS Coalition to Unleash Power (ACT-UP).[72] Over several months, AIDS Institute staff quietly negotiated an agreement by which the Archdiocese agreed to provide AIDS information and education and to make referrals for services and more explicit materials.[71] Eventually, on July 27, 1990, accompanied by protestors armed with whistles, air horns and handcuffs, the NYS Public Health Council voted to exempt Catholic-run AIDS nursing homes from the specific standards of care pertaining to condoms, safe-sex counseling, contraceptives and abortion services.[73]

Diana, Princess of Wales, spent three days in NYC early in 1989. On February 3 she visited a pediatric AIDS unit at Harlem Hospital.[74] Media coverage, including a photograph of the Princess holding a young boy, highlighted the impact of the HIV/AIDS epidemic on infants, many of whom were abandoned in the hospital and became known as "boarder babies." In the days following Diana's visit to Harlem Hospital, community members reached out to provide homes for the "boarder babies." Diana's visit also highlighted unresolved policy issues, ultimately leading to program and policy initiatives related to foster care and development of special residences for

children with HIV (i.e., Incarnation Children's Center in Harlem, Birch House in Brooklyn, the Farano Center in Albany).

NYS' HIV ambulatory care strategy was refined in 1989 in response to the development of clinical interventions for early HIV disease and to changes in the epidemiology of HIV infection. The strategy relied heavily on building capacity of community health centers, especially those located in communities where need for care was greatest and where community health centers were accessible to members of the community. The goals of the HIV ambulatory care strategy were to increase early identification of HIV infection by promoting HIV prevention education and counseling and testing in a variety of health care settings; to integrate HIV primary care in community health centers throughout the state; to ensure the provision of services to under-served populations, including minorities, substance users, women, children and adolescents; and, to empower uninsured individuals to access health services. This strategy was pursued through an enhanced Medicaid reimbursement structure called the 5-tier system. Within that system resides the Medicaid HIV counseling and testing reimbursement structure. To be eligible for the enhanced reimbursement, providers have to demonstrate the ability to provide quality services in accordance with defined standards. The AIDS Institute has established systems in place to monitor both quality and utilization of services offered in accordance with the requirements for the enhanced reimbursement. The AIDS Institute further supports quality services through its clinical guidelines, training and technical assistance.

The HIV Primary Care Medicaid Program was established in 1989 to promote early diagnosis and access to quality care for persons with HIV infection. Medicaid reimbursement rates were established for six HIV ambulatory primary care visits: HIV pre-test counseling, HIV post-test counseling for persons who test negative, HIV post-test counseling for persons who test positive, an initial comprehensive HIV medical evaluation (billed once in the lifetime of the patient), drug and immunotherapy services (administration of aerosolized pentamidine) and HIV disease monitoring for asymptomatic HIV-positive persons. While the goal of the Program has remained the same, the reimbursement structure has been revised several times over the years to respond to: advances in HIV treatment and testing technology; evolving standards of care; and to changes in public health policy. Eligibility is open to hospitals and diagnostic and treatment centers that are: licensed under Article 28 of the Public Health Law; approved to participate in the NYS Medicaid Program; and have signed an agreement with the NYSDOH to provide comprehensive services and coordination of care for persons with HIV.

With resources from the CDC and the State, in 1989 the Community HIV Prevention and Primary Care Initiative was funded to meet the growing need for community-based HIV services when preventive treatments became available for delivery in ambulatory care settings. Grants were targeted to local health departments and community health centers willing to develop or expand on-site HIV prevention and primary care services and to hire and train additional staff. Initially, 17 facilities received grants. Later, in 1992, the Community HIV Prevention and Primary Care Initiative added a dental care component to a list of core clinical services provided to persons with HIV. Six grants to support the provision of dental services were awarded. Recipients were four DACs, one local health department and one community-based organization with experience providing HIV dental care.

The Substance Abuse Initiative was first developed in 1989 to provide counseling, testing, referral and partner notification services (CTRPN) in drug treatment facilities, using funds from the CDC. The AIDS Institute and the NYS Office of Alcohol and Substance Abuse Services (OASAS), which oversees the largest drug treatment system in the nation, collaborated on what was the first step

to develop a comprehensive continuum of HIV prevention and primary care services in substance abuse treatment settings across the State to address the intersecting epidemics of HIV and addiction.[75-76] This was regarded as a groundbreaking initiative. Later, in 1991, using NYS funding and funding from the Substance Abuse and Mental Health Services Administration, HIV primary care services were implemented in substance use treatment settings, often referred to as the Co-located HIV Primary Care Program. This initiative brought medical care to sites where substance users already received other services. Various drug treatment service models have participated in this initiative. They include: methadone maintenance; methadone-to-abstinence; drug-free residential; outpatient; and detoxification. The Substance Abuse Initiative has made it possible to overcome numerous barriers to serving substance users. It has been highly successful in engaging substance users to access continuous medical care. The initiative also expanded the mission of the substance abuse treatment community from singular focus on rehabilitation to include other public health issues. Starting in September 1989, DACs with pediatric and obstetrical departments were required to provide specialized HIV care to infants, children, adolescents, and pregnant women in recognition of the increasing incidence of HIV among these populations. Also in 1989, the CDC provided $1.7 million to fund 24 hospital-based programs providing postpartum counseling, testing, referral and linkages to care. The HIV Early Identification and Treatment Services Initiative was designed to meet the needs of pregnant and postpartum women and their infants/children.

In December 1989, a Request for Proposals (RFP) was issued for HIV prevention and services for high-risk women and HIV-infected women and their families. Services included community outreach, preferably by indigenous community health workers; HIV education, counseling and peer support; and supportive and related services such as linkages to help women care for their basic needs and those of their families (e.g., housing; financial and nutrition assistance; child care; homemaker services; medical respite; and transportation).

The OMD's HIV Clinical Education Program was created in that year. The goal was to increase both the number of community medical care providers managing HIV infection and the quality and level of services provided, as well as to improve and solidify referral relationships between community health providers and tertiary care centers. Dr. Rango's recognition of the potential role of physicians in influencing needed changes in the delivery of health care and social services and in the development of new programs to treat people with HIV, led to the creation of the HIV Clinical Scholars Program. This unique program was specifically designed for licensed physicians, physician assistants, nurse practitioners and dentists seeking hands-on training in HIV/AIDS clinical care and the public health aspects of the HIV epidemic.[77] A collaboration between the AIDS Institute OMD and selected DACs in the NYC metropolitan area, the program was designed to increase the number of clinicians committed to providing a continuum of care for individuals with, and at risk for, HIV/AIDS.

To strengthen prevention efforts, in late 1988 a small staff known as Prevention Surveys and Evaluation was created within the Education and Training Unit. Initially, this group focused on evaluation of the Education and Training Unit's programs for professionals (e.g., correctional officers, EMTs, train-the-trainer) and piloted the use of client pre- and post-test surveys from "AIDS 101" presentations given by community-based contractors. They also pioneered the use of surveys to measure the impact of presentations to inmates at intake into the state's prison system. Since there were no available resources for assessing the knowledge, attitudes, beliefs and behaviors (KABB) related to the new epidemic, staff wrote, piloted and modified questions in response to advances in the epidemic. Prevention Surveys and Evaluation was responsible for two major

KABB surveys. The first was a statewide survey of NYS adults and the second was a KABB survey of women of childbearing age in high-risk areas of the Bronx and Brooklyn. Staff was expanded in 1992 to assess counseling and testing efforts, including testing among pregnant women. Today, the Office of Program Evaluation and Research, known as OPER, works to enhance the quality of HIV/AIDS prevention interventions, clinical care and service delivery systems through comprehensive, coordinated, and innovative research and evaluation initiatives in collaboration with other AIDS Institute units and/or with external partners. OPER evaluates Institute-funded or managed programs to determine the extent to which they are achieving their stated objectives; makes recommendations to improve program outcomes; and provides technical assistance. Other services include: literature reviews; grant and institutional review board application assistance; evaluation planning; sample selection; development of evaluation instruments; and study implementation, including training, data collection, data analysis, and summary of research findings. OPER collects and analyzes data used for AIDS Institute program planning and policy development (e.g., Community Need Index).

1990 On January 10, 1990, the AIDS Institute convened the Committee on the Care of Women and Children with HIV Infection at Mohonk Mountain House, together with: representatives of the NYSDOH; the NYS Department of Social Services; the Division of Human Rights; the Division of Substance Abuse Services; and the Division of Alcoholism and Alcohol Abuse (these two Divisions were later merged to form OASAS). The purpose was to identify ways in which the State could best care for and support, as well as prevent HIV/AIDS among women and children in order to develop policy recommendations. Issues considered included: proposed mandatory or routine newborn screening for HIV; NYS' policy on testing of women; models of service delivery; and integration of substance abuse treatment with health and social services. A statement of principles, often referred to as the "Mohonk Principles," was prepared to guide program and policy. The conference supported policies on voluntary counseling and testing of pregnant women and advocated that medical and social support services targeting HIV-positive women and children be expanded. The Mohonk Principles laid the foundation for broader newborn and prenatal testing by describing criteria that should lead to this increased testing.[78] These principles were used in later years to guide development of programs to eliminate HIV transmission from mother to newborn and to ensure HIV-infected women were offered state-of- the-art treatment. A second conference, convened in January 1992, provided for expert review of the "Mohonk Principles" and reaffirmed their ongoing relevance.

By Spring 1990, when it was estimated that 200,000-350,000 New Yorkers were infected with HIV, the NYSDOH launched a campaign to encourage all health care providers to routinely counsel patients about AIDS and encourage voluntary testing. This shift in Departmental policy from a "neutral position of informing people about the test to recommending it for those at risk"[79] was supported by FDA approval of AZT in 1987, which had added emphasis to the benefits of testing and treatment. The campaign targeted physicians in specific settings (i.e., criminal justice settings, drug treatment programs, STD clinics, prenatal care and family planning programs and seven hospitals that had the highest rates of HIV infection among childbearing women). At the same time, it was recognized that comprehensive HIV prevention strategies, including efforts to deal with underlying social and environmental issues, active participation of the community and greater societal resolve were needed.[80]

In April 1990, 18-year-old Ryan White died of AIDS.[24] The following month, Congress authorized funding for the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act to improve the quality and availability of care for low-income, uninsured and underinsured individuals and

families affected by HIV/AIDS. When federal Ryan White funding became available in 1991, the foundation for NYS' system of community-based health care and services was already in place. Ryan White funds were used, along with NYS and CDC resources, to expand and broaden this system. Specifically, Ryan White resources were used to augment existing initiatives, most notably the ADAP and home care programs for the uninsured. The resources extended primary care services to the uninsured; funded new, community-based case management and supportive services programs; and established Ryan White HIV Care Networks throughout NYS. The Act was reauthorized in 1996, 2000, and 2006. It is the centerpiece of federal support for persons infected with HIV.

The first authorization of the Ryan White CARE Act directed most of the new funds to cities, not to the states that were charged with developing comprehensive systems of care. NYS had benefitted from assistance and support from Ms. Julie Scofield, who worked in the Governor's Washington, D.C. office. By 1990, Dr. Rango recognized the need for the states to have a unified voice at the federal level and charged the AIDS Institute's Director of GRASP (Governmental Relations and Strategic Planning) with mobilizing state health departments. In 1991, staff began calling AIDS Directors in other states and the AIDS Institute convened eight high-incidence states for a meeting in NYC to discuss the feasibility of joint meetings related to federal funding for care and prevention programs. The states found that they had much in common and also that there was no good reason to limit participation to high incidence jurisdictions. As staff attended national meetings and conferences, they sought out and enlisted state AIDS Directors. Conference calls provided a forum for discussion. A Steering Committee of AIDS Directors formed to consider systems and procedures to support the group's work. The AIDS Institute began to refer to the group as the National Alliance of State and Territorial AIDS Directors (NASTAD) and began to plan a national meeting that would be held in Washington, D.C., including development of a successful proposal to the Gund Foundation for funding to bring the AIDS Directors together without reliance on any federal funds.

Also beginning in 1990, the DOH began to issue "Dear Colleague" letters to health care providers caring for women. These letters were often sent in conjunction with the American College of Obstetricians and Gynecologists, the American Academy of Pediatrics and other NYS professional medical associations. The 1990 letter, sent to prenatal care providers, focused on recommendations for routine HIV counseling and voluntary testing of all pregnant women. The AIDS Institute's Obstetrical Initiative was implemented in August 1990, supported by funding from the CDC and NYS. It provided hospitals in NYS with start-up funding for HIV services targeted to postpartum women at increased risk for HIV infection who may have had little prenatal care or prior contact with the health care system. The Initiative was designed to provide HIV counseling and testing services to women in the obstetrical units of 24 hospitals in NYS. Participating hospitals were identified through the newborn seroprevalence study as having a high number of HIV-positive women delivering babies. A NYS-NYC work group, involving staff from both Health Departments as well as the NYC Mayor's Office, was convened monthly.

In April 1990, the AIDS Institute, in collaboration with the NYC Human Resources Administration (HRA) and the then five NYC-based HRSA-funded Pediatric AIDS Demonstration Projects that had been funded since 1988, submitted a proposal to HRSA in response to a competitive solicitation entitled "Pediatric Acquired Immune Deficiency Syndrome (AIDS) Health Care Demonstration Projects."[81] The AIDS Institute and its collaborators proposed the following: a coordinated Citywide planning process; a model computerized clinical/case management system; integration of medical, social and other needed services; and provision of the highest quality prevention and treatment services to HIV-infected women, children and adolescents. The proposal also included development of a "super center" umbrella entity called, the "Pediatric HIV/AIDS Comprehensive

Care Center" to facilitate family-centered case management in NYC and a broadly-constituted Steering Committee, composed of the AIDS Institute, HRA and representatives of the five HRSA-funded Demonstration Projects.

This project, known as PAFCC (for Pediatric, Adolescent, Family Comprehensive Care) was funded effective September 1, 1990. PAFCC fulfilled a valuable role by bringing together providers, state and city agencies, existing advisory bodies and others to develop program and policy initiatives. As additional direct service projects were funded by HRSA with subsequent Ryan White funding (eventually there were nine), they joined the collaboration. PAFCC continued through 1999 and provided a forum for the AIDS Institute and providers to jointly identify the most effective program models, resource allocation strategies and to advance clinical care as new knowledge and treatments emerged. Direct contact with providers and consumers was invaluable as the epidemic evolved.

The Community Follow-Up Program (CFP), implemented in 1990 based on an amendment to the NYS Medicaid plan, is a statewide initiative within NYS' Comprehensive Medicaid Case Management program that provides family-centered, intensive case management services.[82] It was created pursuant to section 9508 of the federal Consolidated Omnibus Budget Reconciliation Act (COBRA) of 1985 for optional targeted case management services under Medicaid. The targeted Medicaid-eligible populations included HIV-infected persons and their families and high-risk individuals for a temporary period of time. The CFP model utilized a team of case managers and paraprofessionals to provide comprehensive, intensive case management. The Case Management Section recognized the need to measure case management outcomes, doing so in collaboration with Union College in Schenectady, NY. Programmatic effectiveness and cost effectiveness were demonstrated[83-85] and issues related to job satisfaction were explored.[86] A later study, conducted in collaboration with the University of Connecticut, documented the role of case managers in helping their HIV-positive clients disclose their HIV-infection status to others.[87]

In 1990, the Legal Services Initiative was established to enable low-income, HIV-infected people and their families to gain access to legal professionals who provide help in writing wills; making child custody arrangements; combating discrimination; accessing health care services and entitlements; specifying terminal care preferences and proxies; and maintaining or acquiring housing. This legal assistance was essential for people with HIV-related disease who could not otherwise manage or afford legal counsel.

With the recognition that good nutrition is essential to the management and treatment of HIV infection and AIDS, 1990 also saw the implementation of the AIDS Institute's Nutrition Program. Through contracts with local agencies, the program was designed to meet the nutritional needs of persons living with HIV/AIDS (PLWHA). Through home-delivered and congregate-meal programs, it provided optimal nutrition to help maintain or improve the health of individuals with HIV/AIDS.

Seroprevalence studies had documented a high rate of HIV infection among inmates, with rates of nearly 20% for both men and women correlated with a history of injection drug use in the community.[88-91] In NYS, an increase in court commitments for drug offenses increased the percentage of IDUs in NYS prisons.[92] In fact, the first reported, confirmed case of AIDS among US prison inmates had been from NYS in November 1981.[93] In 1990, the first program in the Criminal Justice Initiative was initiated. The Prison Project provided HIV/AIDS prevention education and voluntary counseling and testing services to inmates housed in NYS Department of Correctional Services' facilities. It also provided HIV/AIDS prevention education to facility staff. AIDS Institute staff traveled long distances to directly provide these services within correctional facilities until 1991 when the Criminal Justice Initiative (CJI) funded CBOs to offer HIV prevention and support

services within DOCS' facilities.[94] Over the years, the programs and services provided in DOCS through the CJI evolved and expanded based on: assessments of needs;[95] AIDS Institute participation in national pilot projects;[96-98] availability of resources; changes in intervention science; and advances in HIV testing technology.[99] The CJI has made HIV counseling and testing and prevention services available to inmates in local county correctional facilities, often referred to as jails.[100-101] The AIDS Institute has continued to work with DOCS and others on various initiatives, including: transitional or "discharge" planning; educational programs for inmates with communicable diseases;[102] a program for continuity of care for inmates with hepatitis C;[103] and improving access to mental health services.[104]

In October 1990 the AIDS Institute held its first statewide conference, "Into the 90s: The Second Decade of the AIDS/HIV Epidemic," at The Sagamore in Bolton Landing, on Lake George. With more than 500 individuals in attendance, demand for a session that offered insights on garnering support of local, state and federal elected officials was so strong that the session was repeated a second day.[105] With the exception of 1995 and 1998, statewide conferences were held annually through 2000, at which time fiscal constraints precluded the convening, by state agencies, of such events.

1991 With the growing epidemic came sharp increases in the number of children orphaned by the death of their parent(s) due to HIV/AIDS and perinatally infected children in the foster care system. By 1991, it was estimated that 3,900 children and 3,600 adolescents in NYC alone had been orphaned by AIDS.[106] AIDS Institute staff worked with staff from: other NYSDOH programs; other state agencies; City agencies; and others to develop and maintain adequate guidance for foster parents as well as health and human service organizations providing care and services to children in foster care. For instance, DSS Administrative Directives and regulations covered a range of issues such as: HIV assessment; counseling and testing; consent; training for staff and foster parents; required services following HIV testing; confidentiality; disclosure of information; and recordkeeping.[107-108] Financing of specialized foster care services, made available through DSS and OCFS since 1987, provided necessary support to foster parents and to foster care agencies. The AIDS Institute remained actively involved in interagency efforts, working with OCFS and others. Later, in 2003, the AIDS Institute and OCFS jointly published, "Caring for Children with Special Needs," a manual for parents, foster parents and other caregivers. The manual was developed with input from members of Families Making a Difference (FMAD). FMAD consists of individuals with firsthand experience in caring for children either infected with HIV or affected by the disease. The manual addressed all aspects of caring for children with HIV/AIDS in a user-friendly, culturally and linguistically appropriate fashion.[109]

On February 25, 1991, Commissioner Axelrod, a nationally acclaimed public health leader, suffered a debilitating stroke. Following Dr. Axelrod's retirement in May, Governor Cuomo selected Dr. Mark R. Chassin as Commissioner.[110-112] On October 23, 1991, the NYSDOH, the New York Academy of Medicine and the Josiah Macy, Jr. Foundation cosponsored a symposium, "Dr. David Axelrod and the Health of the Public: Looking Ahead." Dr. William Roper, Director of the CDC, acknowledged Dr. Axelrod and the AIDS Institute, saying "the nation has learned from you."[113, p. 212] Dr. David Rogers, Chair of the NYS AIDS Advisory Council spoke about the lack of national will and contrasted NYS with Washington, saying "New York has done better than any other state or nation. . . in dealing with AIDS."[114, p. 215] He described the AIDS Institute as ". . . an absolutely remarkable group of dedicated, ornery, pushy individuals who have been instrumental in shaping New York's response to AIDS."[114, p. 215] Upon his death in July1994, Dr. Axelrod was further remembered for his leadership in NYS' response to AIDS and for his work to fund AIDS programs, services and research.[112]

In 1991, the Mayor of NYC established the HIV Health and Human Services Planning Council of New York. The Council is charged with developing spending priorities and allocating Ryan White CARE Act, Title I (now Part A) funds based on the needs of the ever-changing HIV/AIDS epidemic. The 50-member Council is a coalition of persons living with HIV/AIDS; service providers; caregivers; governmental representatives; and community members. The vision of the Planning Council is that people living with HIV disease in the NYC metropolitan area (NYC, Westchester, Rockland and Putnam Counties) will have access to appropriate, quality services across the continuum of care, resulting in the best possible health and quality of life. Since its inception, AIDS Institute staff have represented the AIDS Institute on the Council. The Planning Council has been instrumental in keeping HIV/AIDS issues at the forefront and ensuring continued funding and services in the NYC metropolitan area. Similarly, the AIDS Institute has maintained an active role in Planning Councils on Long Island and in Dutchess County.

Clinical care guidelines, developed by the AIDS Institute's Committee for the Care of Children and Adolescents with HIV Infection, were published in 1991 as a supplement to *The Journal of Pediatrics*.[115] These were the first clinical guidelines in the nation for the care of infants, children and adolescents with HIV/AIDS. They also addressed other medical needs as well as the social aspects of caring for HIV-infected youth. They were the only such guidelines in the US until the CDC's release of the "Guidelines for the Use of Antiretroviral Agents in Pediatric HIV Infection" in April 1998, which was more narrowly focused on antiretroviral treatment.[116]

Regional Community Education Committees were established in 1991 to enhance the sharing of information, strategies, and materials between the AIDS Institute and HIV/AIDS educators throughout the state. The Committees served a number of functions, including reviewing and reacting to proposed strategies or initiatives from the AIDS Institute; commenting on HIV/AIDS educational materials such as posters, brochures, and videos; making recommendations to the Institute based on successful programs and activities; sharing expertise with other communities; and responding to and developing regional HIV educational training resources.

For people with HIV infection and AIDS, day-care programs operated by nursing facilities, such as the one that opened in 1989 at the Village Nursing Home, provided a range of needed services to promote independence and to avoid or postpone admission to a hospital or nursing home. Regulations promulgated in August 1991 created a new service category of AIDS Day Health Care to expand availability of services by enabling diagnostic and treatment centers to also apply for NYSDOH licensure. To meet the growing need for AIDS day care, using an appropriation for this purpose, the AIDS Institute solicited proposals and awarded planning grants to developed additional AIDS day care programs. Over the years, the AIDS Institute's licensed nursing home and clinic based AIDS Adult Care Program continued to meet the emerging needs of PLWHA.

AIDS Adult Day Health Care Programs target services to individuals living with HIV/AIDS who are often poor; homeless; psychiatrically/mentally impaired; chemically dependent; formerly incarcerated; or otherwise disenfranchised from the health care system. Programs are designed to provide a comprehensive and integrated model of service delivery in a cost-effective manner by avoiding duplication of services and minimizing the need for patients to attend additional off-site services. They provide a comprehensive range of services in a community-based, non-institutional setting. Among the services provided are, general medical care including: treatment adherence support; nursing care; rehabilitative services; nutritional services; case management; HIV risk reduction; substance abuse; and mental health services. AIDS Day Health Care Programs serve clients with medication adherence issues; those who are in need of medical monitoring for chronic medical conditions; and those who are dually or triply diagnosed with HIV/AIDS, substance abuse,

and mental illness. Programs receive a fixed Medicaid-reimbursed per diem for services delivered, which includes transportation and capital costs. Clients are required to attend the program for at least 3 hours for each billable visit and must, over the course of a week, receive 3 hours of health-related services.

The AIDS Home Care Program was implemented in November 1991 to provide long-term home health care services to chronically dependent individuals with HIV illness or AIDS, and who have no or limited insurance for home care. Home health aide services, skilled nursing visits, intravenous therapy administration, medication and supplies, laboratory tests and durable medical equipment were covered. Statewide coverage was ensured through enrolled home care agencies.

Starting in 1991, the AIDS Institute provided funding to support two adult residences (Bailey House in NYC, and Benedict House in Buffalo) and began working with NYS and NYC agencies having responsibility for addressing housing needs to assure that persons with HIV/AIDS were included in planning for housing. In 1992, authorization of HOPWA (Housing Opportunities for People With AIDS) brought federal funds to support local efforts to develop HIV/AIDS housing initiatives. Over the intervening years, the AIDS Institute has worked closely with national, state and local agencies and organizations to meet housing related needs. With increasing recognition of the impact of housing on health and well-being, the phrase, "Housing is Health Care," became a national theme. Housing initiatives in NYS, which benefitted from increased funding that resulted from national advocacy, were developed using results of specific housing needs assessments. Today, the AIDS Institute funds and oversees enhanced supportive housing, housing placement assistance and referral services as well as one-time emergency financial assistance. In addition, the AIDS Institute is a participant in New York New York III (NY/NY III), a cooperative agreement between NYC and NYS agencies to develop housing for chronically homeless populations. The AIDS Institute and the NYC Human Resources Administration are charged with the development of 1,000 supportive housing units for PLWHA who have a history of chronic homelessness and of either mental illness or substance abuse.

In 1991, in response to the frequently articulated need to cover the cost of transportation to access critically needed services for many HIV-positive individuals, the AIDS Institute launched its Transportation Initiative. This initiative provided resources to support the arrangement and provision of transportation services to assist individuals living with HIV and AIDS in accessing necessary and appropriate health and supportive services. It also assisted individuals whose behavior placed them at high risk for HIV infection in accessing HIV counseling and testing.

Beginning in December 1991, community-based programs were funded to implement HIV prevention services targeting high-risk women and HIV-infected women and their families. Currently the Women's Services Unit has eight programs throughout NYC which provide: outreach (conducted by indigenous health workers); HIV education and referrals; counseling; support groups; and individual and family counseling. In addition, they provide client services for families, including housing, as well as financial and nutritional assistance. Some of these programs are "peer initiative" contracts.

The HIV Enhanced Fees for Physicians (HIV EFP) Program was established in 1991 to provide enhanced Medicaid reimbursement to private physicians willing to treat patients with HIV in primary care settings, thereby building greater capacity for HIV primary care.[117] HIV EFP patient visits included pre-test counseling (with and without testing); post-test counseling (negative and positive); annual comprehensive exam; drug and immunotherapy services; and CD4 monitoring. Participating physicians were required to: be in private practice and enrolled in the

NYS Medicaid Program; have active hospital admitting privileges; be Board certified; provide 24-hour coverage; and coordinate medical services, including hospital admissions and referrals for specialty care and social services.

As the AIDS Institute's responsibilities expanded, so did its need for internal management systems. Created in 1991, the Bureau of Information Resources Management had responsibility for supporting the data needs of the AIDS Institute and for systems development and implementation. Specific responsibilities included: developing research and evaluation protocols; advising on data collection and reporting strategies; and implementing Institutewide management information systems (e.g., the Contract Management System). In 1994, this Office was renamed the Information Systems Office (ISO). ISO was charged with managing, maintaining, analyzing, and reporting data and information-related activities of the AIDS Institute. ISO provided management with information to carry out NYS' response to the AIDS epidemic. Today, ISO is the AIDS Institute's information technology center, providing the following: technical assistance and systems support; web site support; software development; database management; statistical analysis; and other services.

1992 Within the AIDS Institute, the Office of Administration and Contract Management provides policy direction and oversight of all activities related to grants and contract management, budget development and fiscal management, and operations management. The Office works to ensure that funds from all sources, including State, CDC, and HRSA funds, as well as Medicaid, are devoted to the development and implementation of the continuum of HIV prevention, care and supportive services throughout NYS. It oversees the allocation of AIDS Institute resources; provides assistance and technical support to contractors and staff regarding fiscal and contractual matters; and provides consistent systems and procedures for contract management, grants management, procurement, cash management, internal controls and operational issues. By 1992, it was clear that a computerized system was needed to effectively manage the information associated with funds for which the AIDS Institute was responsible. A Contract Management System (CMS) was developed using spreadsheet software. CMS was redeveloped in 1998 as a relational database and redesigned, again, in 2001. Over time, CMS evolved into a management information system that supports site visit planning, scheduling, and reporting; manages solicitations, applications, and the outcomes of competitive procurements; provides geo-mapping of providers and service sites; and tracks Medicaid providers and reimbursements. Multiple uses include reporting to funders, planning bodies, legislators and other agencies; development of responses to Freedom of Information Act requests; provision of data for the Community Needs Index; development of resource directories; and the development of a wide range reports used for program planning and management.

The *Journal of Public Administration Research and Theory*, in April 1992, published the results of a project funded by the federal Agency for Health Care Policy. "New York State's Response to AIDS: Evolution of an Advocacy Agency," provided an account of the larger policy context for the HIV/AIDS epidemic in NYS, including a description of the early years of the AIDS Institute.[113] The authors noted the broad policy influence of the AIDS Institute

> ". . . in areas as diverse as social services, drug abuse, prisons and education. Even though the social services agency distributes Medicaid, the AIDS Institute has influenced the policy under which Medicaid funds are distributed for AIDS cases. The AIDS Institute is thus a state agency that has national and even international significance as a model for those interested in fighting AIDS."118, p. 179

Dr. Rango provided opening and closing comments at the first annual meeting of NASTAD, held in Washington DC on March 31 and April 1, 1992. Dr. Rango took federal officials to task for their failure to do more to support states in their efforts to confront the growing epidemic. At the meeting, thanks to the efforts of the Steering Committee, the AIDS Directors were able to ratify bylaws, to hold elections for an Executive Committee, and to adopt care and prevention position papers. In association with NASTAD, AIDS Institute staff compiled, "Briefing Book: Implementation Status of the Ryan White CARE Act (Title II) In States and Territories As of May 1992," that reflected a narrative discussion and data from every state and a letter to Senator Arlen Spector that was signed by the AIDS Directors of the eight high incidence states. Remarkably, in June 1992 a letter to Senator Tom Harkin urging increased support for Ryan White CARE Act Title II funding bore the signatures of 26 Governors from a variety of states, including New York's Mario Cuomo.

In May 1992, the NYSDOH filed emergency regulations authorizing the State Health Commissioner to exempt personnel and participants of approved syringe exchange programs from the State's needle possession law as an HIV prevention measure. The regulation required syringe exchange services be provided as part of a comprehensive harm reduction model.[119] In addition to provision of clean injection equipment, harm reduction services included: information on risk reduction practices related to sexual and drug-using behaviors; distribution and demonstration of condoms and dental dams; distribution and demonstration of bleach kits and safer injection techniques; and direct provision of or referrals to HIV counseling and testing, drug treatment program, health care services, legal, housing, and social services. That same year, the state's first authorized syringe exchange programs (SEPs) were approved. Syringe exchange was effective in preventing transmission of HIV and hepatitis C. Studies of trends in HIV and hepatitis C virus (HCV) infection among injection drug users in NYC from 1990 to 2001 documented a significant decline in HIV prevalence (from 54% to 13%) as well as declines in HCV prevalence (from 80% to 59%) among HIV-seronegative individuals and from 90% to 63% overall.[120] AIDS Institute staff also found syringe exchange to be cost effective.[121] The AIDS Institute and the NYSDOH Bureau of Health Economics had previously used cost-effectiveness analysis to document for infection control practitioners the cost effectiveness of needle stick prevention technology in health care settings.[122]

The Women's Supportive Services Initiative, within the Women's HIV Prevention Services Unit, was inaugurated in NYC to expand the availability of HIV-related services for women and their families and to strengthen the referral linkages between hospital HIV counseling and testing programs (i.e., the Obstetrical initiative) and community-based health and social services. The initiative was a jointly funded, public-private partnership, in which the AIDS Institute provided programmatic oversight, and the United Way of New York City provided technical assistance and fiscal administration. Ten community-based organizations were initially funded to provide family-centered case management and community follow-up and support services as well as other concrete services to HIV-infected women and their families. In the spring of 2009, the AIDS Institute assumed sole oversight of the Initiative which currently includes thirteen (13) organizations.

To further understand the demographics and needs of HIV-infected children and resources available to meet those needs, the Division of HIV Health Care commissioned the Center for Health Policy Studies to conduct a "Pediatric HIV Continuum of Care Study."[123] This study was conducted with input from a 30-member Advisory Committee comprising state and City agency representatives, academicians, health and human service providers, legal experts, educators and behavioral scientists. They collected epidemiologic data and information from service providers statewide regarding children served during 1990 and services provided to them. Completed in July 1992, the study documented a large population (1,459) of HIV-infected children in NYS, most of whom were

in NYC, and who were largely receiving care and services. For example, of the 1,459 children, 87% received outpatient medical care, 40% required inpatient care, 49% of family members received case management and 26% of family members participated in support groups. Significant gaps were found in upstate areas (where services were concentrated in only four hospitals) and transportation, case management and home health care were lacking. NYC providers expressed concerns about lack of affordable day care and problems accessing home health care services for some families. While increased residential care for HIV-infected children was not needed, there was a need for more case management services.[123] Findings guided program development and allocation of resources.

The ADAP Plus Program, a primary care initiative, was implemented in October 1992 to provide access to primary care services statewide to low-income persons not covered by Medicaid or adequate third-party insurance. ADAP Plus was developed with funding through a unique partnership between NYC and NYS.

Since 1992, through its HIV Quality of Care Program, OMD has overseen and coordinated quality improvement activities including: the development of clinical performance measures derived from practice guidelines; on-site quality of care reviews, promotion of quality improvement activities; peer learning opportunities for HIV care providers; and consultations with providers to support on-site and off-site quality improvement efforts. The HIV Quality of Care Program has built the capacity of HIV providers in NYS to self-report their annual performance data. In 2009, more than 180 health care facilities throughout NYS have reported their performance data based on more than 11,000 patient charts. The results of these reviews are provided to each facility in individual reports as well as aggregate data of the entire annual review, and whenever possible, longitudinal data. Statewide quality of care program standards have been developed which apply to all HIV health care facilities, regardless of their caseload, location or service delivery model. These standards ensure that the best clinical care is provided to patients throughout NYS by improving systems of care delivery and by stimulating quality monitoring. In addition to medical chart reviews, organizational assessment tools have been created and routine evaluations with all NYS HIV providers are conducted to determine the extent to which these program standards have been implemented. Data from annual assessments of providers' quality management programs guide technical assistance and consultation to further enhance providers' quality management programs. These data are also used to develop strategies to advance the statewide Quality of Care Program.

The Quality of Care Program coordinates the participation of internal and external stakeholders through several distinct groups to further advance the statewide Quality of Care Program and to remain responsive to the continuously changing nature of HIV clinical management. For the past 15 years, the Clinical Advisory Committee, comprised of clinical experts across NYS, has provided guidance to establish priorities for measurement and advised the AIDS Institute on policies for the HIV Quality of Care Program. To programmatically include people living with HIV/AIDS (PLWH/A) in planning, implementing, and evaluating Quality of Care Program activities, OMD established its Consumer Advisory Committee in 2002. In 2007, a Young Adult Consumer Advisory Committee was formed to solicit feedback from HIV-infected adolescents and to routinely present their concerns in AIDS Institute committees.

As a result of fund raising and a modest dues structure, modeled after that of ASTHO (Alliance of State and Territorial Health Officers), NASTAD opened a Washington office in the fall of 1992 and recruited candidates to consider as Executive Director, selecting Ms. Scofield. NASTAD was incorporated as an organization in October 1992. The AIDS Institute has participated continuously in NASTAD's Executive Committee and it has remained actively involved in NASTAD since its

inception, providing in-kind support as well as leadership on program and policy matters. Ms. Scofield has commented that,

> "NYS was the first state to organize comprehensive systems of care for people with HIV/AIDS and is still the model. People do not appreciate the complexity of the epidemic in NYS. . . .even though NYC was directly funded, the AIDS Institute adopted a statewide approach and took as its mission the entire state." (J. Scofield, personal communication, September 24, 2008).

NASTAD has grown from one staff to 30 to35 in its Washington office and includes both domestic and global initiatives as part of its mission.

With an increasingly diverse population, NYS needed a highly-developed approach to address HIV/AIDS, including an improved understanding of the ways in which social, cultural and ecological factors shape health behaviors and influence health status. Also needed were steps to address closely related issues, such as drug use and sexually transmitted diseases, as well as engagement of a diverse array of community-based agencies and organizations.[124] In no other public health discipline has this need been as acute and compelling as it has been in HIV/AIDS. This need was recognized by the communities most affected by HIV/AIDS, the AIDS Institute, other parts of the NYSDOH, the NYS Legislature and the Governor.

A continuing objective of the AIDS Institute has been to allocate resources in a manner consistent with the changing epidemic. To ensure this process occurred in the most effective fashion, in 1992 the AIDS Institute, in conjunction with the AIDS Advisory Council, codified a series of principles for funding allocation decisions entitled the "Fair Share" principles. The principles were designed to guide funding allocation decisions in response to the escalating HIV epidemic among communities of color. The intent of the principles was to ensure the distribution of resources in HIV-affected communities toward equitable levels over time, with consideration to changing conditions and circumstances including intensity of risk, prevalence of infection, maturity of community and program structures, and other relevant factors. The "Fair Share" principles were:

1. To regard prevention and health care/support services as equal priorities.
2. To support knowledge-building to achieve risk reduction among all affected communities and the general public.
3. To regard all affected communities as equally deserving of prevention and care services.
4. To balance allocations between health and support services based upon judgments about relative and timely need.
5. To support continuity and collaboration in service delivery through comprehensive case management.
6. To support integration of prevention activities with health and social services.
7. To support programs for underserved populations; drug users, individuals in the criminal justice system and others.
8. To distribute funds among communities of increased risk in response to the changing dynamics of the HIV epidemic.
9. To build infrastructure capacity/capability of agencies providing prevention and health/social services within affected communities.
10. To distribute resources in HIV-affected communities equitably, with consideration of risk level, HIV seroprevalence, maturity of community and program structures.

Consistent with the "Fair Share" principles, the Multiple Service Agency (MSA) Initiative and the Community Development Initiative (CDI) were initiated in 1992. The intent of the MSA was to expand the capacity of organizations serving minority communities to provide "one-stop" HIV services within high-need areas of NYS. The model was designed to be developmental, allowing organizations to phase in a comprehensive array of services, including HIV prevention, client services and community development. CDIs would identify and develop community leaders who can speak to and for the community with authority and credibility; provide means for ongoing, culturally competent dialogue; engage local media; and promote community coalitions to mobilize communities, drawing upon strengths of indigenous leaders (as well as individual community members) in support of community health and well-being. As the next logical step in developing a community-based infrastructure, the MSAs and CDIs complemented the CSP initiative and expanded service capacity. Like the CSP initiative, the MSAs and CDIs were phased-in over several years based upon state appropriations and competitive solicitations. Both MSAs and CDIs address sociocultural aspects of HIV/AIDS. They do so in distinctly different, yet complementary, ways to confront continuing disparities in health status and HIV/AIDS-related health outcomes faced by specific populations.

1993-1997 Continued Development of Programs and Services

This section discusses important themes of the AIDS Institute's work during this period, such as:

- *Development of programs and services for women, newborns and children in response to the growing awareness of the maternal-pediatric epidemic.*
- *A strong program of consumer and provider support and engagement though such mechanisms as the Statewide AIDS Service Delivery Consortium, the HIV Prevention Planning Group and the People Living with HIV/AIDS Leadership Training Institute.*
- *Response to broad health care reform initiatives such as managed care, including initiation of steps to develop HIV Special Needs Plans.*
- *Expansion of programs and services in response to the introduction of combination antiretroviral therapies for HIV.*
- *Dissemination of additional clinical guidelines, quality improvement tools and development of additional infrastructures for monitoring delivery of programs and services.*
- *Focus on specific populations such as adolescents, young adults, homeless persons and gay men/men who have sex with men, including young men of color who have sex with men.*

1993 In January 1993, *Newsday* highlighted experiences of women who learned of their own HIV or AIDS diagnosis – or that of their partners – only after their partners had become very ill or had died.[125-129] Within weeks, Queens Assemblywoman Nettie Mayersohn resolved to take action to protect women and newborns. She proposed legislation to require reporting of names of all HIV-infected persons to local health departments and mandatory notification of any named contacts.[130] With knowledge of the state's blinded newborn screening, Ms. Mayersohn introduced the "Baby AIDS" bill in May 1993. This bill would unblind newborn screening and insure that the mother would be notified of the baby's test result.[42]

By 1993, the AIDS Institute moved away from direct delivery of training and instead began funding training centers throughout the state. The Education and Training Unit was moved into the OMD and efforts were made to ensure coordination between training for clinicians and non-clinicians. By 1995, Unit staff no longer offered direct training but contracted out to regional training centers. This allowed Unit staff to assume the role of curriculum developers, thereby diversifying the panel of HIV/AIDS trainings available through the training centers. In 1993, training centers offered three different courses. By 1997, training centers offered more than 12 different trainings on a wide variety of topics (e.g., behavior change, cultural diversity, harm reduction, HIV and STDs, clinical management of HIV).

In June, *The New York Times* published a profile of Dr. Nick Rango, highlighting his impatience with the overall response to HIV/AIDS, including on the part of the elected officials and the State Health Department.[52] Five months later, at age 49, Dr. Rango died of AIDS at home in Manhattan. His obituary highlighted his national influence on AIDS issues and the evolution of the AIDS Institute during his tenure, including quadrupling of its budget and expansion of programs and services.[131]

The Fourth Annual Statewide HIV/AIDS Policy Conference held in November 1993 was dedicated to the memory of Dr. Rango. The Conference agenda packet included a one-page tribute to Dr. Rango, containing a photograph of him and the following quotes:

> The AIDS epidemic. . . has claimed another towering figure. Dr. Nicholas Rango's ferocious struggle against the disease has been a beacon in the storm. . . . He created new medical and treatment models, and sometimes by the force of his own personality forced into being new housing and community care programs. He has made an enormous difference in the lives of thousands of HIV positive New Yorkers. . . his loss is a costly one indeed for the entire Family of New York. (Mario M. Cuomo, Governor, New York State)

> Nick Rango was a passionate pioneer, a passionate physician who blended the doctor's caring and healing role with the policy making role of a public health advocate and leader. . . . he broke new ground constantly in the fight against the disease which took his life. The AIDS Institute itself is a living legacy. . . . Unorthodox, impatient and courageous in his public fight against the disease, he was equally valiant in his personal struggle. The Department of Health and the world of public health will miss him greatly. (Mark R. Chassin, M.D., Commissioner, NYS Department of Health)

Dr. Rango was succeeded by Dr. Nilsa Gutierrez, appointed as Director of the AIDS Institute in February 2004 by Dr. Mark Chassin, who had succeeded Dr. David Axelrod as Commissioner of Health after Dr. Axelrod passed away in July 1994. Dr. Gutierrez had provided leadership during Dr. Rango's illness and served as AIDS Institute Director until her resignation in late 1995.

The NYS Legislature appropriated additional funding for health and supportive services for women and children with HIV. This funding supported the development of co-located HIV/gynecological services; health facility-based comprehensive services for women and children; and community-based supportive services for women and their families. Due to the large response to the competitive solicitation of these funds, the Institute successfully negotiated with the NYC Ryan White Title I Planning Council for additional funds to increase the number of awards that could be made to NYC providers. In addition, the AIDS Institute, through active partnership with the Planning Council, proposed and got funding contributions from Part A towards the uninsured care pools. These contributions have continued, at different levels, to this day.

In 1993, NYS and other jurisdictions were challenged to respond new reporting requirements implemented by HRSA for funds awarded under the Ryan White CARE Act. In order to be able to fulfill the requirements, the AIDS Institute designed a Uniform Reporting System (URS) to be used by all AIDS Institute-funded providers receiving Ryan White funding. An RFP was released in 1994 to solicit a software vendor to develop the URS in accordance with Ryan White requirements. Subsequently, the AIDS Institute Director, Dr. Nilsa Gutierrez, decided that there should be a single system for all funds administered by the AIDS Institute (e.g., Ryan White, CDC, NYS). This decision meant that the AIDS Institute was the first in the nation to have a single data system for client-level data for all funding sources, many years before this became common practice. NYS was able to respond to changing federal requirements by modifying and building on to their existing system, allowing continuity in client data management for funded providers. Inclusion of a module for Medicaid billing for COBRA case management services further enhanced the value of the system to providers (e.g., CSPs), giving them an incentive to use URS beyond the basic functions associated with grants management. After some deliberation and encouragement from the provider community, in 1996 the NYCDOHMH and MHRA adopted the URS software for their contract management and Ryan

White reporting requirements. For several years, NYS remained one of a handful of jurisdictions with coordinated, statewide, client-level data systems. In 2007, in conjunction with a redesign to meet changing federal requirements and benefit from changes in information technology, the URS became known as AIRS (AIDS Institute Reporting System). The system continues to grow and build functionality in response to provider needs and federal requirements.

Also in 1993, working with an interagency work group consisting of state and NYC agencies, the AIDS Institute implemented a Community Placement Pilot Program to provide housing and supportive services in NYC for homeless persons with HIV and TB who were in need of directly observed therapy or who were HIV-infected and in need of preventive therapy for TB. Housing needs remained a focus throughout 1993-1994, with community meetings convened to elicit input from consumers and providers. The AIDS Institute has continued to work with NYS and NYC agencies to provide adequate housing for persons with HIV and their families. A study of HIV-infected Medicaid recipients in NYS, published in 2000, examined health care utilization patterns and found that unstably housed persons are less likely to receive adequate care and more likely to experience adverse clinical outcomes.[132]

At the request of the Legislature, the AIDS Advisory Council, under the leadership of Dr. Rogers, convened a Subcommittee on Newborn HIV Screening, known as the "Blue Ribbon Panel." Its charge was to review issues and policies and to make recommendations that would have the greatest potential for identifying infants and women with HIV and bringing them into care. The Blue Ribbon Panel recommended mandatory HIV counseling for all pregnant and postpartum women, rather than mandatory newborn testing.[133-135] Days later, the results of the clinical trial "076" were released showing the effectiveness of zidovudine (ZDV, formerly called AZT) to prevent mother-to-child HIV transmission.[136] The AIDS Institute sent "Dear Colleague" letters, provided training and technical assistance to providers caring for pregnant women and their newborns and developed provider and consumer materials.

1994 A comprehensive model for counseling and testing and clinical care of pregnant women and their newborns was developed. Between May and December 1994, the AIDS Institute's clinical guidelines program developed and disseminated the first perinatal HIV prevention guidelines in the US.

In 1994, the AIDS Institute released a brochure and video titled, "For Women Only: What Women Can Do to Protect Themselves From HIV." These were developed with input from an expert panel, convened in 1991 to review what was known about sexual risk reduction options. From this review, a hierarchy of sexual risk reduction was derived. The hierarchy presented methods to decrease the likelihood of sexual transmission of HIV. The brochure recommended the male condom as the most effective barrier to HIV transmission and female-controlled methods (e.g., female condom, diaphragm with spermicide, spermicide alone) were also suggested if the male condom was not a possible choice. Later, after research did not demonstrate a protective benefit of the microbicide, nonoxynol-9, and additional behavioral studies of HIV prevention interventions for women,[137-139] the AIDS Institute convened another expert panel. Following the expert panel meeting and focus groups with providers and with sexually active women, a new brochure, "Choices for Women: What Females of all Ages Can Do to Protect Themselves from HIV," was released in 2000. "Choices" featured a longer, more detailed introduction including a statement for women living with HIV or AIDS. It presented the male and female condom together as the first option (the previous version listed them as separate options). Additional sections addressed anal sex and oral sex, pregnancy prevention and STD prevention as well as the use of lubricants and spermicides. "Choices" was designed to help women make an informed choice, given the limits of what was known at the time. It was considered effective in its delivery of a complex public health message.

To better understand the HIV risks of women who have sex with women, the AIDS Institute analyzed self-reported data from women who accessed HIV counseling and testing through the ACT Program for an 18-month period during 1993-1994. Injection drug use was found to be the predominant risk factor among HIV-infected women who were sexually active with other women.[140] This information underscored the importance of considering IDU as a potential risk factor for women who are sexually active with other women and of HIV counseling and testing for all women who have engaged in risk activities, regardless of sexual orientation.

Continuity of care systems for HIV-positive individuals traveling between Puerto Rico and Puerto Rican communities on the US mainland, including in NYC, was critical. Beginning in 1994, the Air Bridge Network was a collaborative effort between federal, state and local governments, a medical center, four community health centers and an AIDS service organization. AIDS Institute participation had been strongly supported by Dr. Rango, who was quoted in *The New York Times* as saying that, ". . . air travel made it one epidemic."[141] The Air Bridge Network demonstration project promoted a better understanding of the existing migration patterns of HIV-positive individuals. It identified available services and developed a pilot system for coordinating care for HIV-positive persons traveling on the "air bridge." AIDS Institute staff also examined federal policy barriers to immigrants infected with HIV.[142] The Air Bridge continued to provide valuable services through December 2005.

Other notable milestones during 1994 included the formation of the Statewide AIDS Service Delivery Consortium (SASDC) to address the needs of specific populations (i.e., MSM of color; homeless persons; prison releasees and probationers; mentally ill chemical abusers; immigrants; and migrants) and creation of the NYS HIV Prevention Planning Group (PPG) to advise the AIDS Institute on HIV prevention priorities. The PPG, a diverse, statewide group, was established in response to a national initiative to promote HIV prevention community planning through requirements linked to CDC HIV Prevention Cooperative Agreement funding.[143-144] December 1994 also marked a transition for the AIDS Advisory Council when Dr. Rogers, its Chair, passed away.[145] Dr. Allan Rosenfield, Dean of Columbia University's Mailman School of Public Health, became Chair of the AIDS Advisory Council upon his appointment to the Council.

The Adolescent Prevention Services Section was created in 1994 to expand and strengthen prevention services for young people. Later that year, the Gay, Lesbian and Bisexual Initiative was developed to support culturally competent organizations within the gay, lesbian and bisexual communities and to increase the cultural competence of other HIV service providers. The AIDS Institute also launched a Peer Initiative, guided by input from organizations using the peer model of service delivery and from individuals working as peers in their communities.

In November 1994, George Pataki narrowly defeated Mario Cuomo for Governor. Governor Pataki selected Barbara DeBuono, M.D., M.P.H. as Health Commissioner. Dr. DeBuono remained Commissioner of Health through November 1998.

1995 The NYS Legislature appropriated $6.5 million to implement the new standard of care and clinical guidelines for perinatal ZDV therapy in 1995. The Early Identification and Intervention Services (EIIS) Initiative provided grants to hospitals with high HIV seroprevalence among women giving birth. Funding was used to support HIV counseling in prenatal settings and prenatal/obstetrical care for positive women and newborn/pediatric care for their exposed infants. "Dear Colleague" letters were sent to health care providers and a statewide teleconference, "Preventing Maternal-Child Transmission," was held. Quality of care reviews focusing on pediatric HIV care and prevention of mother-to-child transmission were initiated in 1995. The Wadsworth Center established the Pediatric HIV Diagnostic Service, offering free polymerase chain reaction (PCR)

diagnostic testing for all HIV-exposed infants born in NYS. The pediatric PCR testing service allowed for definitive diagnosis of babies by using qualitative DNA testing to look for the virus, not antibodies. Specimens for babies testing positive through DNA testing are further examined to assess how much virus is present as well as how resistant the virus is to antiviral therapy. NYS is the only state that has this component of its statewide HIV/AIDS program.

In 1995, using funds appropriated for this purpose, the AIDS Institute implemented the Permanency Planning Initiative to support appropriate arrangements for child custody and care while a parent with HIV is ill and after that parent's death. Through Chapter 83 of the Laws of 1995, the NYS Legislature requested that the AIDS Institute, in conjunction with others, produce a report on children orphaned by HIV/AIDS and a plan for comprehensive permanency planning in NYS. The following year, the *Families in Crisis* report[146] acknowledged the importance of programs supporting HIV-affected families, offered projections of children and youth who would be orphaned by the end of 2001 and provided numerous program and policy recommendations.

The AIDS Institute's PLWHA Leadership Training Institute (LTI) was founded to provide training; skill-building; motivation; and education to PLWHA in community organizing; HIV advocacy; and public policy development. Conceived and developed by PLWHA, the LTI offers individuals living with HIV/AIDS a safe space to explore individual leadership strengths and goals; a better understanding of leadership opportunities in the AIDS community; experience in problem solving approaches to community issues; a strengthened ability to have a voice in the processes that determine what AIDS services are appropriate and needed; and an increased sense of personal empowerment. Many LTI graduates have contributed substantially to advisory bodies to the AIDS Institute (e.g., PPG, consumer advisory committees) and many have held leadership positions in local, state, national and international organizations.

The AIDS Institute continued to work on funding streams to support appropriate HIV care. Reform of the state's Medicaid program was also underway. In 1995, the state submitted a Section 1115 waiver application to the Health Care Financing Administration (HCFA). The following year, three pieces of legislation were passed to restructure NYS' Medicaid program by authorizing the implementation of a statewide program of mandatory Medicaid managed care plans. These milestones allowed for development of HIV Special Needs Plans (SNPs), once HCFA approved the state's waiver application in July 1997. In fact, specialized managed care plans to address the health and medical needs of persons with HIV/AIDS had begun to be explored in 1994 with the award of a five-year Special Projects of National Significance (SPNS) grant from the federal Health Resources and Services Administration. The SPNS project underscored the critical importance of building upon the existing infrastructure of programs and services in NYS, developed largely by the AIDS Institute. Work began on conceptualization of an approach that was ultimately reflected in an HIV Special Needs Plan Request for Applications, released in May 1999.

In 1995, Rivington House, the largest residential AIDS facility in the nation, opened in NYC. Rivington House, now known as The Nicholas A. Rango Health Care Facility, offers comprehensive clinical services, including skilled nursing care, to meet a range of physical, mental and spiritual needs of PLWHA. This was historic in that it was the last AIDS nursing facility to be opened.

The introduction of combination antiretroviral therapies for HIV in 1995 had a dramatic effect in reducing progression of HIV to AIDS and AIDS deaths.[147-150] It also raised issues related to access to and use of antiretroviral therapy,[151] increased complexity in pharmacologic management of HIV infection[152] and the respective roles of generalists and specialists in HIV care.[153] Rapid growth in the enrollment and expenditures of NYS' ADAP program also occurred. This growth prompted a series of events that contributed to the expansion of access to care for thousands of people

nationwide. During 1995 all ADAPs faced financial burdens due to the advent of highly active antiretroviral therapy. While the lifesaving aspect of combination therapy profoundly changed the course of the epidemic, the cost of combination ARV therapy was unreachable for the nation's low-income uninsured people living with HIV and AIDS. In 1996 Congress recognized this crisis by adding specific funding for ADAP to the Ryan White CARE Act. Combination therapies also made it possible for persons living with HIV/AIDS to return to the work force. Treatment adherence became particularly crucial because: 1) initial regimens included multiple pills and complicated schedules that were difficult to adhere to and 2) HIV develops resistance to combination therapy very quickly if medication doses are missed or delayed.

In the months and years that followed, the AIDS Institute provided necessary program and policy leadership[154] to assure that all New Yorkers had access to life prolonging and enhancing medications and medical care. The NYS ADAP grew from a short-term grant program that was funded with $8.3 million, to a comprehensive health care access program that will spend more than $300 million on care, treatment and insurance coverage for more than 22,000 people living with HIV and AIDS in 2009. In order to secure the best price for ARV therapy and stretch limited federal funding, the ADAP Crisis Task Force was formed. The Task Force is made up of 10 ADAP directors who negotiate, on behalf of ADAPs nationwide, with pharmaceutical manufacturers for reduced costs for ADAP-covered medications. New York State's ADAP Director is a member of the Task Force.

The OMD also responded with the development of a number of activities to support, enhance and evaluate treatment adherence, including comprehensive treatment adherence demonstration programs[155-158] and guidance for occupational and nonoccupational post-exposure prophylaxis.[159] With the emergence of drug resistance as a cause of treatment failure, the AIDS Institute, in collaboration with the Wadsworth Center and others, explored the prevalence of primary drug resistance and the role of resistance testing to inform treatment decisions.[160-161]

In November 1995, in response to being asked to find ways to cut the AIDS Institute's $180 million budget by up to 20% and to make staff reassignments and terminations, Dr. Nilsa Gutierrez resigned as Director of the AIDS Institute, saying, "I will not be an accomplice to a process that dismantles HIV care in New York State."[162] There were widespread concerns on the part of community members about how the AIDS Institute would fare under the new Governor and the new Health Commissioner, Dr. Barbara DeBuono. Charles King, Co-executive Director of Housing Works, said, "Of all the government entities in the country addressing HIV, it has been the most daring about challenging the status quo."[163] Commenting on staff dismissals and reassignments, Dennis DeLeon, President of the Latino Commission on AIDS, noted "They're taking people out who have institutional memory. It's a program to destroy the Institute and merge it with DOH."[163] In December 1995, Dr. Guthrie S. Birkhead was appointed as Acting Director of the AIDS Institute. In response to community concerns about the future of the AIDS Institute, the Department eventually issued a Press Release stating that, "There is absolutely no factual basis for the claim that the AIDS Institute has been dismantled or weakened."[164]

Despite Governor Pataki's moratorium on state regulations, a Consented Newborn HIV Testing Program was advanced as a policy initiative, with impetus from two lawsuits that had been brought against the state by the Association to Benefit Children.[165] Governor Pataki explained that, "We are changing the policy of New York State to put the health and the lives of infants foremost."[166]

1996 Changes to State regulations (Part 69-1), implemented May 1, 1996, required all DOH-regulated prenatal providers to routinely provide HIV counseling to all pregnant women, to make a clinical recommendation for voluntary prenatal testing and, with the mothers' consent, to provide the newborn's HIV test results to mothers.[167] Statewide training sessions were held

to facilitate implementation of the regulations. Regulatory oversight was provided to monitor implementation of the regulations and technical assistance was provided as needed. As the consented testing program was being implemented, support was growing for Assemblywoman Mayersohn's "Baby AIDS" bill, which was reintroduced.

In June 1996, legislation was passed to require the Commissioner to establish a comprehensive HIV newborn testing program, to include HIV testing, with identifiers, of all newborns with results reported to the birth hospital for provision to the pediatrician and to the mother. On June 26, 1996, the "Baby AIDS" bill was signed into law by Governor Pataki, giving the NYSDOH the authority to implement mandatory newborn screening.[168]

On September 24, 1996, Dr. Birkhead, who had served as Acting Director of the AIDS Institute since December 1995, after Dr. Gutierrez' departure, was appointed by Dr. DeBuono as the AIDS Institute's fourth Director.

1997 In January 1997, NYSDOH provided guidance to health facilities and providers on the implementation of the comprehensive Maternal-Pediatric HIV Prevention and Care Program (MPHPCP). The MPHPCP integrated regulations relating to prenatal and newborn testing into the EIIS program for reducing perinatal HIV transmission and ensuring comprehensive care for HIV-positive women and their infants. Routine newborn screening began in NYS on February 1, 1997, in conjunction with the new, comprehensive MPHPCP. Another statewide teleconference focused on implementation of the MPHPCP. A 30-minute audiotape was produced in conjunction with the American College of Obstetricians and Gynecologists (ACOG). Monitoring of all birth facilities was initiated using newborn screening data. This program ultimately resulted in a 90% decline in mother-to-child transmission from 1997-2006.

In the spring of 1997, the AIDS Institute initiated a re-examination of HIV prevention needs of gay men and men who have sex with men (MSM). The Gay Men/MSM Leadership Forum comprised more than 100 representatives of public and private organizations as well as individuals active in the gay community and PPG members. Over a nine-month period, Forum members conducted focus groups, surveys and literature searches; examined data, and discussed trends, programs and policies. While acknowledging that progress had been made, the Leadership Forum recommended that approaches to effectively address the epidemic needed to continue to evolve. Recommendations for action were provided for funders, policymakers, health and human service providers, researchers and organizations providing services to gay men/MSM.[169]

By 1997, 15 % of newly reported AIDS cases in NYS were among persons age 50 and older. The AIDS Institute, in collaboration with the PPG members and others, conducted focus groups to learn more about how HIV prevention messages could best be tailored to meet the unique needs of older adults[170] and explored ways to bridge service delivery systems so missed opportunities to meet the prevention and care needs of older adults could be addressed.[171] The AIDS Institute reached out to the NYS Office for the Aging (SOFA) and others to foster broad dissemination of new "Age is No Barrier" brochures and posters. Later, in 2002, a statewide video conference, entitled, "HIV/AIDS Over 50," was held in collaboration with SOFA, OCFS and the State University of New York at Albany.

On September 10, 1997, Governor Pataki signed an Executive Order that reappointed state agencies to the Interagency Task Force on HIV/AIDS. The Executive Order provided specific tasks to be accomplished, including establishment of a relationship with the AIDS Advisory Council, development of a mechanism to continue beyond the two-year time frame provided for in the Executive Order and development of a progress report with recommendations. Two reports containing the progress report and recommendations were published in 2000.[172-173]

In 1997, the HCFA approved NYS' Section 1115 Medicaid waiver. HIV SNPs, as defined in the NYS Medicaid Managed Care Act of 1996, were intended to provide an alternate source of capitated managed care to Medicaid-eligible persons with HIV infection. Using the 1994 SPNS grant as a cornerstone, the AIDS Institute had initiated HIV SNP development.[174] Activities included: awarding $2 million in grant funds for planning purposes; initiating a research study designed to evaluate the health care experiences of persons with HIV infection as they transition from a Medicaid fee-for-service program to a capitated managed care environment; and passage of legislative language authorizing the creation and licensure of HIV SNPs. These activities culminated in federal approval of the Department's application to implement SNPs. HIV SNPs, fully operational since 2003, provide an alternative source of care to Medicaid-eligible persons in NYC with HIV/AIDS. Medicaid-eligible individuals have the option of enrolling in an HIV SNP, a mainstream managed care plan, or receiving services through the traditional fee-for-service system. HIV SNP networks are broadly composed, encompassing the full continuum of HIV services currently available in NYS. Inclusion of health and human service providers with experience in the provision of HIV services enables SNPs to meet the complex medical and psychosocial needs of enrollees, either through direct service provision or by referral. Clinical care provided by SNPs is in accordance with AIDS Institute-established standards for HIV care and assessed through continuous quality improvement techniques.

The "Alternate Sites" program, established in 1985 to provide an alternative option to blood banks for those seeking to know their status as one of the state's earliest responses to the HIV/AIDS epidemic, evolved over the years and became known as the Anonymous Counseling and Testing (ACT) Program. The ACT Program has long offered testing in both community and criminal justice settings. Originally, all testing involved venipuncture (blood drawing). As new HIV test technologies became available, the ACT Program incorporated them into its services. For instance, in 1997, the ACT Program introduced oral fluid testing and later, in 2003, it implemented rapid testing. Although testing was anonymous, an option to convert a positive test result to confidential status to expedite entry into care was also made available. Technological advances led to other improvements, such as elimination of mailing of paper copies of test results when secure electronic transmission via the Internet could deliver test results almost immediately.

Also developed in 1997, the HIVQUAL Program is a partnership between the AIDS Institute and HRSA's HIV/AIDS Bureau. The primary goal was to build capacity and capability for quality improvement among Ryan White Part C and Part D grantees. HIVQUAL has aimed to improve the quality of care delivered to persons with HIV in ambulatory care programs in NYS and across the country. Built upon the principles of quality improvement and models developed through the NYS HIV Quality of Care Program, HIVQUAL has guided programs to build and sustain quality management programs. Consultants are made available to provide support and coaching to assist facilities in this process. Key principles of the model include using aggregate data to measure performance, measuring core HIV clinical indicators based on clinical practice guidelines, and providing quality improvement (QI) consultations. Specific strategies include building internal organizational systems to sustain an HIV-specific quality program; facilitating QI initiatives using multidisciplinary teams; providing education about QI tools and methodologies; encouraging peer learning opportunities; and promoting support and commitment throughout the organization for quality. Self-reporting of performance data based on indicators that are in alignment of practice guidelines is a critical component for this national program. In 2007, the national data set has included 168 Ryan White-funded Part C and Part D grantees (including those from NYS), representing over 10,000 chart reviews.

1998-2002
Ongoing Evolution of NYS Response, Policies and Program Models

This section discusses continuation of NYS' response to the HIV/AIDS epidemic. Some highlights during this period included:

- *Enactment of a bill to create what became known as NYS HIV Reporting & Partner Notification Law, followed by development and promulgation of regulations, large-scale implementation and a CDC-funded evaluation.*
- *The need for a shift in perspective and new programs (e.g., treatment adherence) in response to recognition of HIV/AIDS as a chronic, manageable disease.*
- *Implementation and evaluation of the Expanded Syringe Access Demonstration Program, a public health program to syringe access and promote safe syringe collection and disposal.*
- *Formal launch of a Faith Community Initiative at a two-day statewide conference and formation of Regional Committees of faith leaders and others.*

1998 Since early in the epidemic, HIV/AIDS has been a disease of men who have sex with men, injection drug users and communities of color in NYS. The Legislature, the Department and the AIDS Institute recognized the unique needs of communities of color and responded with programs such as the Multi-Service Agencies and the Community Development Initiative implemented in 1992 and the Peer Initiative launched in 1994. In 1994, with the advent of HIV Prevention Community Planning, the AIDS Institute and the PPG worked together to identify HIV prevention needs, interventions and strategies. AIDS Institute initiatives continued to target the prevention, care and supportive service needs of communities of color in ensuing years, guided by community and provider input as well as deliberations and published reports of the AIDS Advisory Council,[175-176] ongoing collaboration with the PPG and an internal Communities of Color Work Group. CDC's release, in 1998, of national data on the HIV epidemic highlighted the disproportionate impact on communities of color, particularly African-Americans.[177] National attention to the impact of HIV/AIDS on communities of color in the US was immediate[178-182] and has been sustained to this day.

In response to the exposure of several young women in rural Chautauqua County by someone believed to have known his HIV status,[183] the AIDS Institute coordinated a public health response in collaboration with the CDC and the Chautauqua County Department of Health.[184] ACT Program staff from several regions were mobilized to offer HIV counseling and testing at sites throughout Chautauqua County.[185] There was also a surge of renewed interest in identifying persons with HIV infection and their partners. A bill, introduced by Assemblywoman Mayersohn, became Chapter 163 of the Laws of 1998, often referred to as the NYS HIV Reporting and Partner Notification Law, effective in January 1999. Names of individuals diagnosed with HIV/AIDS and names of any partners known to the medical provider were required to be reported to the NYSDOH, with screening for risk of domestic violence added as a required component of HIV partner notification.[186] The community reaction was intense.[187] Following extensive consultation with the community and providers and, literally, hundreds of comments on proposed regulations, final regulations to implement provisions of the HIV Reporting and Partner Notification Law were effective June 1, 2000.

Following the departure of Dr. DeBuono in November 1998, a new Health Commissioner, Dr. Antonia C. Novello, was nominated and appointed by Governor George Pataki after Senate confirmation. Dr. Novello, known as an advocate for women, children and underprivileged and underrepresented populations, forged ties with the community by talking about AIDS and inspiring audiences with her compassion and commitment, including, for example, at the Statewide HIV/AIDS Policy Conference, World AIDS Day events and in a variety of public forums.

With advances in treatment that could delay disease progression and improve quality of life, adherence to antiretroviral therapy was receiving greater attention. A new Treatment Adherence Initiative was established to assess and assist consumers at risk for non-adherence, focusing on consumer and provider collaboration to develop consumer-specific strategies that lead to sustained adherence. Development and dissemination of information, strategies and tools for clinical providers; forums for providers and consumers to share adherence best practices; review of emerging adherence research and program designs; and sharing of successful strategies and practice experiences with health care and social service providers ensued. Technical assistance to integrate treatment adherence methodologies and training into community-level clinical education and service programs was made available, as were educational materials and training for consumers. AIDS Institute-funded treatment adherence programs implement strategies to promote adherence to HAART through client-centered, multidisciplinary approaches. Members of the health care team work with consumers to develop, implement, and evaluate tools and skills-building activities to increase and sustain adherence to therapy.

In December 1998, members of the New York Capital Region Chapter of the NAMES Project hosted a display of the AIDS Memorial Quilt in conjunction with the annual World AIDS Day observance. Beginning in 1999, the AIDS Institute has collaborated with the New York Capital Region Chapter of the NAMES Project to host an annual display of panels from the AIDS Memorial Quilt in the Empire State Plaza Convention Center. Youth peer educators provide HIV prevention education to school groups. The AIDS Institute and the New York Capital Region NAMES project work closely with peer educators to provide them with appropriate training using the AIDS Memorial Quilt as an education tool, as well as current information on HIV/AIDS prevention. Schools throughout NYS are invited to visit the Quilt display and receive HIV prevention education. The annual World AIDS Day observance also includes presentation of awards to individuals, organizations and clinicians from across the state who have made an outstanding contribution to fighting the epidemic.

A validation study conducted by AIDS Institute staff, in collaboration with the Wadsworth Center and health care providers, using data from the MPHPCP for the period August 1, 1995 through January 31, 1997, showed a possible benefit from an abbreviated course of ZDV prophylaxis given to prevent perinatal HIV transmission. In 1998, the results were published in *The New England Journal of Medicine*.[188] The study demonstrated that abbreviated regimens of ZDV prophylaxis given to the mother in labor, or immediately afterwards to her newborn, could reduce transmission. This landmark study led to changes in clinical guidelines at the state, national and international levels.

1999 In response to the findings that abbreviated regimens of ZDV prophylaxis given to the mother in labor, or immediately afterwards to her newborn, could reduce transmission,[188] the NYSDOH implemented regulations for the MPHPCP in August 1999. Birth facilities were required to assess the HIV test status of the woman presenting for delivery with unknown status and to offer the mother expedited HIV testing with consent or, if she declined, to test the newborn. The expedited test result was required to be returned within 48 hours. The goal was to offer ARV prophylaxis to the mother during labor or to the newborn when there was a positive expedited test.

In response to a directive from Congress, the Institute of Medicine conducted an evaluation of "the extent to which State efforts have been effective in reducing. . .perinatal transmission."[42, p. vii] in recognition of the progress made in NYS, the Institute of Medicine reached out to Dr. Birkhead as a resource for this evaluation. The published report, *Reducing the Odds: Preventing Perinatal Transmission in the United States*, was released in 1999. It included a 27-page Appendix titled "Passing the Test: New York's Newborn HIV Testing Policy, 1987-1997" that provided a detailed chronology and overview of NYS' response as well as "key lessons"[42, p. 313] from NYS that were considered especially significant to inform program and policy development for the nation and for other states. Despite the impressive progress in reducing mother-to-child transmission of HIV in NYS that was reflected in the Institute of Medicine report,[42] the AIDS Institute and the Department continued to look for ways to further prevent infants from becoming HIV-infected.

Also in 1999, the CDC and the HRSA announced availability of funding, made available through the Congressional Black Caucus, to support criminal justice demonstration projects. The NYSDOH AIDS Institute and the NYCDOHMH collaborated on a joint application. NYS, five other states and one city received awards, as did two organizations funded to coordinate and evaluate the project and two organizations funded to provide technical assistance. Within the AIDS Institute, the Bureau of Direct Program Operations and the Bureau of Community-Based Services launched a complex. multi-component project encompassing activities at certain NYS prisons; in an upstate county correctional facility; in NYC's Rikers Island facility; and in the state's juvenile justice system. HIV/AIDS prevention services were offered in all project settings, peer education (including in Spanish) was offered in prisons, disease testing was offered in prisons (for HIV) and juvenile facilities (for gonorrhea and chlamydia), transitional ("discharge") planning was offered in jails, and staff training was offered in jails and in the juvenile justice system. This project, which remained operational through 2003, offered valuable insights for service delivery within the criminal justice system, Lessons learned from this project were applied to other programs and the work that was initiated has continued through other funding sources. The project further strengthened the already strong relationships among and between the AIDS Institute, DOCS, OCFS, jail staff and CBOs.[98] It also identified the need to build further relationships with the NYS Division of Parole and the NYS Division of Probation and Correctional Alternatives.

In 1999, additional steps were taken to revisit the HIV prevention needs of gay men. First, in January 1999 the AIDS Institute held a statewide provider conference in Albany, titled, "MSM/Gay Men HIV Prevention Strategies for the Future." Next, the NYS Black Gay Network held a Summit in April, followed by a strategic planning retreat in September. In December, funding to support the NYS Black Gay Network was awarded based upon the results of a competitive solicitation. These activities highlighted the need for more programs and services, including those for young MSM of color (discussed below in relation to the Young Men's Study) and an application for supplemental funding from the CDC. The following spring, at the AIDS Institute's statewide HIV/AIDS policy conference, the NYS Black Gay Network received the Dr. David E. Rogers HIV Prevention Award.

With technical assistance from the AIDS Institute and new State funding, the NYS Department of Labor funded a demonstration project to help HIV-infected welfare recipients find and maintain appropriate employment. The goal of the HIV Welfare to Work Pilot was to enhance the employ-ability of HIV-positive persons by connecting them with jobs that provided health insurance coverage and assisting them in maintaining their health status by staying engaged in care and receiving needed support services. The amount of $2.8 million was awarded in August, 1999, to six agencies for the provision of vocational training; case management; psychosocial support; job placement; and post-employment services to meet this goal. The AIDS Institute worked

collaboratively with the Department of Labor to oversee the implementation of this initiative including participation in contractor meetings and program evaluation. Based on contractor feedback and evaluation information, in 2002 the AIDS Institute provided technical assistance to the Department of Labor in making changes to the program design to enhance development and expand the program's capacity and reach to target populations. The administration of Welfare to Work programs were moved from the Department of Labor to the Office of Temporary and Disability Assistance (OTDA), and in 2006 and 2007 the AIDS Institute continued to work with OTDA to develop a new, HIV, Welfare-to-Work RFP. The Institute assisted in RFP reviews, rating of applications and selection of contractors. As of January 1, 2010 there are seven HIV Welfare to Work contractors who receive a total of $2.6 million in State funding.

2000 In January 2000, the NYS Interagency Task Force on HIV/AIDS (IATF) published the *New York State Interagency Task Force on HIV/AIDS: Service Program & Policy Inventory 2000*.[173] This report provided brief descriptions of current programs, services and policies of 25 NYS government agencies related to HIV/AIDS. In April, the *New York State Interagency Task Force on HIV/AIDS: Final Report to the Governor, April 2000* was released.[172] The *Final Report* summarized major accomplishments of the IATF and its Work Groups, as well as recommendations for continued future collaboration among NYS government agencies. These reports fulfilled the charge to the Task Force set forth in Executive Order #54, signed in 1997.

The Community Action for Prenatal Care (CAPC) Initiative was launched in 2000 to support goals of the comprehensive MPHPCP through the development of community coalitions dedicated to the reduction of perinatal HIV transmission through recruiting high-risk pregnant women into prenatal care in targeted zip codes of the South Bronx, Central Brooklyn, Northern Manhattan, and Buffalo.[189] In each area, a lead agency coordinates activities of a local coalition to reach high risk pregnant women who are not in prenatal care. A comprehensive model features a social marketing campaign; a 24-hour a day/7-day a week, confidential, toll-free hotline; extensively trained outreach workers; referrals from agencies serving high-risk women; intake and transitional case management; user-friendly prenatal systems with clinical consultations to providers; and case management/advocacy. In 2004, CAPC was extended to Rikers Island to reach and engage pregnant female inmates so that they may be linked to community-based services upon release. Further support for the MPHPCP was provided by the Prenatal Care Provider Training Project (PreCARE), implemented in 2000, to provide consultations, technical assistance and training to prenatal care providers and birth facilities.

With its heavy reliance on nonprofit organizations, the AIDS Institute was a founding member of the NYS Board Training Consortium (SBTC), consisting of: the NYS Office of Alcoholism and Substance Abuse Services (OASAS); NYS Office of Mental Health (OMH); NYS Office of Mental Retardation and Developmental Disabilities (OMRDD); the NYS Department of Health AIDS Institute and Center for Community Health; and NYS Office of Children & Family Services (OCFS). SBTC supports the effectiveness of Board members of funded nonprofit organizations. Based on an RFP that had been issued in the summer of 1999, a training contractor began work early in 2000. The SBTC's, "Achieving Excellence in Governance," training series is intended to empower Board members of affiliated nonprofits throughout NYS with the information and tools necessary to carry out their responsibilities and obligations. This training consortium was an unprecedented collaboration of state agencies to promote excellence in governance of the nonprofits whose programs are funded and regulated by NYS. In many cases, these nonprofits provide a substantial portion of direct care and support services to individuals and families.

The Quality of Care Program developed a strong performance measurement system throughout NYS to assess the quality of HIV care. The measurement of quality of care is based on indicators that are linked to optimal clinical care outcomes. Specific aspects of clinical care are selected by providers and consumers through formal decision-making strategies as priorities for performance measurement. The portfolio of performance indicators includes clinical indicators for adults/adolescents and pediatric patients. The Clinical Advisory Committee frequently discusses changes in HIV clinical management and recommends modifications to indicators to ensure that they remain current. In 2000 and, subsequently, in 2002, the AIDS Institute released first-ever HIV public data releases allowing providers to benchmark their performance. The goal of these data releases is to stimulate continuous quality improvement in health care facilities so that the best clinical outcomes can be achieved. A companion consumer guide has been developed to facilitate the understanding of performance data results among the HIV consumer community. This publication marked a national milestone in public reporting in HIV care.

By the year 2000, HIV/AIDS was increasingly being recognized as a chronic, manageable disease. This shift had implications for the AIDS Institute's existing chronic care initiatives, created in the late 1980s to deal with HIV/AIDS as a terminal illness. This shift also raised new issues, such as the need for effective strategies for patient self management,[190] and questions, such as how best to treat persons living with HIV/AIDS who have other chronic diseases and conditions. In response, the AIDS Institute embarked on a reassessment of programs and services to make them more responsive to the changing nature of HIV disease.

The ADAP Plus Insurance Continuation Program (APIC) began July 1, 2000, as part of the HIV uninsured care pools program, better known as ADAP programs. APIC pays the premiums of individuals who have lost their employment and who are eligible to continue their insurance, or working individuals who cannot afford their insurance premiums. Currently one in five people enrolled in the HIV Uninsured Care Programs has an additional form of health care coverage. The program is able to coordinate benefits with the additional coverage, leverage its value and reduce overall program costs. Coverage of drugs and services is revised based on available funding and the changing clinical profile of the HIV/AIDS epidemic.

As noted above, regulations that implemented NYS' HIV reporting and partner notification law became effective June 1, 2000. The law required named reporting of persons with HIV infection, HIV-related illness, and AIDS, by physicians and laboratories. While reporting of known partners was required by physicians, individuals testing HIV positive were not required to name partners for the purpose of partner notification. An intimate partner violence screen for each identified partner was also required.[191-192] Notification could be deferred in cases involving risk of violence.

The complexity of the law, its potential for misinterpretation and its potential impacts were of widespread concern. At one point, AIDS activists had chained themselves to the desk of the AIDS Institute's Director in Albany in protest of the law.[193] They were eventually escorted from the building by uniformed NY State Police. Despite efforts on the part of the Department to allay community apprehension, concerns about the law persisted.

Some people opposed to the new law accuse state officials of deliberately misleading HIV-infected people into thinking they have to report their partners. They fear authorities will intimidate or pressure infected people to report, even if they don't want to. "They are creating the impression of mandatory notification, although it's completely voluntary," said Ronald Johnson, associate executive director of Gay Men's Health Crisis. . . . State officials deny that contention. 'That's just

not the case," Birkhead said. When we get our materials and training. . . out there it'll be clearer that. . . it is voluntary."[194]

CDC recognized the national significance of the policy issues raised by NYS' law and provided funding to the AIDS Institute for a multifaceted evaluation. Conducted by the Office of Program Evaluation and Research, the evaluation ultimately found no negative consequences of the law, including no deterrent effect on test seeking.[195-199] NYS' experiences with implementation of this and other state laws have informed public health practice nationally.[200-201]

With advancements in medical treatment and knowledge regarding the complex relationship among HIV/AIDS, mental illness and substance use, it became clear that a continuum of mental health services was necessary to address the needs of PLWHA. Since 2000, the AIDS Institute has funded agencies for the provision of mental health services within the HIV service delivery system, emphasizing the integration and co-location of mental health services with primary care and substance use treatment services. Over time, a network of mental health providers was established, with service delivery models tailored to specific populations. The range of services includes psychiatric assessment/evaluation, treatment planning, psychotherapy, and care coordination; psychiatric consultation and medication management; and case management. Standards of care, developed by a statewide workgroup of staff and clinical experts, guide provision of quality mental health care.

The NYSDOH launched an innovative initiative, Assets Coming Together (ACT) for Youth, in 2000 to promote youth development as a means to improve health outcomes.[202-203] ACT for Youth shifted the focus from problems and problem reduction to assets and strength-based to improve health by enhancing opportunities and supports in communities for all youth and their families. ACT for Youth was innovative in its emphasis on community building and community change at multiple levels. In February 2000, Governor Pataki issued a Press Release announcing awards totaling $2.6 million to support youth development. Within the NYSDOH, the ACT for Youth initiative is jointly administered by the AIDS Institute and the Center for Community Health. In 2007, NYS' adoption of youth development as a public health approach was the theme of a published Supplement by the *Journal of Public Health Management and Practice*.[204]

In May 2000, the NYS Legislature enacted Chapter 56 of the Laws of 2000 creating the Expanded Syringe Access Demonstration Project (ESAP).[205-206] The goal of ESAP was to reduce the transmission of blood-borne diseases, including HIV and hepatitis, by enhancing access to clean (new) syringes. For the first time in NYS, up to 10 syringes could be sold or furnished to a person 18 years of age or older without a prescription by pharmacies, health care facilities, and health care practitioners who registered with the NYSDOH. Implementation activities included intensive outreach to pharmacies and pharmacists,[207-208] attention to the needs of persons using syringes,[209-210] attention to the need for safe disposal[211-212] and evaluation of community access to syringes through registered pharmacies.[213-214] ESAP was authorized only for the period between January 1, 2001 through March 31, 2003. As with the HIV Reporting and Partner Notification Law, there had been concerns regarding potential negative consequences of this intervention. As a result, the authorizing legislation required an independent evaluation of ESAP.

On September 25, 2000, Governor George Pataki signed another new law, the "Families in Transition Act of 2000." Effective November 25, 2000, this law was intended to remove barriers encountered by families planning for the future care and custody of their children due to the illness or death of a parent or guardian. It also required an annual report of available services and unmet needs of children and adolescents who lost a parent or caregiver to HIV/AIDS.

2001 Release of the results of the Young Men's Study Phases I and II, known as YMS I and II, in late 2000 and early 2001[215-217] received widespread attention. These studies highlighted the extent to which young MSM were putting themselves at risk of HIV infection. Of particular urgency were findings related to young men of color. Locally, attention focused on findings from the NYC study sample and opportunities for the NYCDOHMH and the AIDS Institute to work together to advance HIV prevention by linking services to research and using research to train and inform HIV prevention service delivery. In February 2001, senior staff from NYCDOHMH and the AIDS Institute attended a presentation of YMS I and II by NYC-based researchers and discussed ways to connect HIV prevention, care, supportive services and other referrals to the ongoing research and to integrate an enhanced outreach model into practice. This meeting marked the initiation of a City-State collaboration to develop a project that built upon and extended the research and included CBOs involved in HIV prevention efforts to reach young men of color who have sex with men. The project identified and replicated specific successful methods used in YMS I, II and by CBOs to conduct enhanced outreach to young MSM, particularly young MSM of color, to link them to prevention, care and support services.

On May 14, 2001, the AIDS Institute successfully applied for CDC Supplemental Funds, with support of the NYS HIV PPG, with funding for young MSM of color identified as a priority need. On July 24, 2001, the AIDS Institute released a Request for Applications to support services for young MSM of color and on December 1, 2001, four contracts were awarded for intensive outreach to young MSM of color.

In 2001, the AIDS Institute and funded CBOs adopted Project WAVE, an outreach approach started in Houston, Texas by former radio manager Ernest Jackson, Jr., as a response to the disproportionate impact of HIV/AIDS in the African-American community and in other communities of color. Project WAVE NY's primary goal is to support and enhance community-level HIV counseling and testing events by its member agencies through incentives and other types of assistance, such as "testing for tickets" events (concert tickets, sport events, theater tickets), movie tickets, MetroCards, and gift certificates. Beginning in NYC, Long Island, and Westchester County, Project WAVE eventually expanded its reach statewide.

Also in 2001, after more than 10 years of promoting co-located HIV and addiction services, the Substance Abuse Initiative issued a competitive resolicitation. The goal was to increase the availability and quality of HIV prevention and primary care services for substance users, both in and out of treatment, by incorporating the advances of the past decade into programming. These advances included behavioral-based prevention interventions, harm reduction, new testing technologies, transitional case management, and new standards and best practices in the treatment of HIV/AIDS.

On September 11, 2001, terrorists crashed two hijacked planes into One and Two World Trade Center in NYC.[218] The towers, as well as Seven World Trade Center, collapsed. Nearly 2,800 people died, including civilians, firefighters and police officers. The AIDS Institute was directly affected in many ways. First, staff of the NYC office, located at 5 Penn Plaza, experienced the incident firsthand. Many were at or on the way to work. Many staff knew or had personal relationships with individuals who worked in One and Two World Trade Center. Despite the difficult circumstances, staff mobilized to help assure continued HIV/AIDS programs and services, access to care and access to medications in Lower Manhattan in the face of widespread destruction and disruption of essential services. In the weeks following the attack, contact was made with all AIDS Institute-supported contractors in Lower Manhattan to assess their status and needs in order to

resume operations. These needs were summarized and forwarded to NYSDOH management in case emergency funds became available for distribution.

An evacuation of 5 Penn Plaza due to a bomb threat occurred two days later. Again, the unforeseen nature of this incident in the context of emergency measures that were implemented in NYC in the aftermath of the attacks placed staff in an extremely difficult and stressful situation. There was unclear direction as to how NYSDOH staff located at 5 Penn Plaza should proceed in light of that day's events. One of the consequences was the subsequent development of improved emergency protocols. Shortly thereafter, the AIDS Institute made provisions to temporarily house colleagues from the NYCDOHMH (who were displaced from their offices in Lower Manhattan) at 5 Penn Plaza. The AIDS Institute also responded to anecdotal reports that large numbers of individuals learned of their HIV infection as a result of donating blood in response to the attacks on the World Trade Center, having confirmed that a small increase in the number of seropositive donors was a direct result of an increase in the number of donors, in general.

As national preparedness efforts related to threats of bioterroism included planning for widespread smallpox vaccination,[219] the AIDS Institute monitored issues and concerns related to proposed vaccination of persons with HIV/AIDS[220-221] and developed materials for consumers and providers. Later, as part of the State's commitment to rebuild Lower Manhattan and despite staff concerns, in 2005 the AIDS Institute and other NYSDOH offices were relocated to 90 Church Street, on the northeast corner of the World Trade Center site, which became known as "Ground Zero."[222] The impact of the events of September 11, 2001 led to realignment of priorities and affected the NYS economy and budget process in subsequent years.

Since the beginning of the epidemic, the AIDS Institute has contracted with faith-based community organizations. "A Guide to HIV/AIDS Education in Religious Settings,"[223] published by the AIDS Institute in 1998, provided educational materials and guidelines on HIV/AIDS to more than 12,000 faith leaders. The AIDS Institute conducted a survey of faith leaders to learn more about their involvement in HIV/AIDS prevention.[224] Survey findings helped shape next steps. In 2001, a statewide initiative to reach, engage and involve faith communities in HIV prevention was created and a Faith Communities Project Coordinator was appointed.[225] An overall framework inclusive of all faith communities and traditions was adopted in recognition of the extent of the HIV/AIDS epidemic and the fact that communities of color embrace various religious and spiritual traditions.

The Faith Communities Project was launched with a two-day statewide conference, "Meeting on Common Ground: The Role of Faith Based Communities in HIV/AIDS" in NYC in November 2001. The conference was attended by 275 representatives of faith communities serving racial/ethnic minorities, representatives of AIDS Institute-funded CBOs offering HIV prevention services, volunteers and people living with HIV/AIDS. Regional breakout sessions laid the groundwork for the formation of 12 Regional Committees that subsequently engaged more than 400 individuals in 31 regional needs assessment and planning meetings during 2002. By the end of 2002, action plans for every NYS region were in place. The Regional Committees, consisting of consumers, faith-based representatives, agency staff and interested persons, work with the AIDS Institute to identify needs and to plan and implement regional activities.

2002 It has long been understood that drug treatment can prevent HIV infection. Since 2002, the Substance Abuse Initiative has devoted resources to transitional case management, an effective intervention to connect active substance users with the continuum of addiction treatment services. Programs serving drug users are funded to establish referral relationships with the various components of the treatment continuum (i.e., detoxification, rehabilitation,

drug free, opioid treatment) and to cross-train staff to shepherd users from addiction into recovery, understanding that relapse is intrinsic to the process.

In 2002, the NYSDOH held its first statewide hepatitis C conference, coordinated by staff of the AIDS Institute and other NYSDOH staff involved in hepatitis C-related activities, in collaboration with providers and consumers. Additional hepatitis C conferences were subsequently held annually through 2009. Each conference provided up-to-date information on hepatitis C epidemiology, diagnosis, management, treatment and prevention to assist health and human service providers in offering the most effective care to persons infected with hepatitis C virus. Conference presenters were experts in the field of hepatitis C, drawn from across the US. Each full-day conference offered three plenary sessions and four afternoon workshops. Highlights included presentations on: hepatitis C epidemiology; updates on new hepatitis C treatments; management of the HIV/HCV co-infected patients; best practice models of care; issues in liver transplantation; hepatitis C in the correctional setting; and consumer panels describing the barriers to accessing quality care and treatment. In 2008, conference presentations were expanded beyond hepatitis C to include hepatitis B, as well. Since 2002, the conference has attracted more than 1,000 participants and more than 25 exhibitors.

2003-2007
Refinement in Response to New Technologies, an Evolving Epidemic and an Ever-Changing Environment

This section discusses refinement of NYS' ongoing response, including:

- *A program and policy initiative to streamline HIV counseling and testing (through greater use of rapid tests and a simplified written consent form); integrate routine testing in medical care settings; enhance entry into care of those found to be HIV-infected; and improve monitoring of care through enhanced access to laboratory data (i.e., results of resistance; viral load; and CD4 tests). Expedited testing in labor and delivery settings.*
- *Expansion of HIV rapid testing,(together with Medicaid reimbursement), in various settings, including hospital emergency rooms.*
- *Ongoing emphasis on interventions that have been proven effective (e.g., CDC's Diffusion of Effective Behavioral Intervention ("DEBI") programs; Opioid Overdose Prevention Programs); and expansion of efforts to make condoms widely available through the launch of NYSCondom.*
- *Emphasis on integration of initiatives to address related health issues such as: sexually transmitted diseases; viral hepatitis; tobacco use; substance use; and mental health.*
- *Redesign and resolicitation of program models to address the array of prevention, care and supportive service needs of women, children and adolescents. The goal is to provide cross-institution family-centered care and to support quality clinical services.*

2003 In 2003, CDC implemented the Advancing HIV Prevention Initiative.[226] One key strategy of this initiative was to implement new models for diagnosing HIV infection outside traditional medical settings, including models for incarcerated populations. In 2003, CDC announced availability of funding to support rapid HIV testing in county jails to identify previously undiagnosed cases of HIV infection and refer HIV-infected inmates to care, treatment and prevention services. NYS and three other states received awards and collaborated with county jails to implement rapid HIV testing. This project, which remained operational through 2006, provided valuable insights into offering rapid HIV testing to county jail inmates, regardless of whether an inmate reports HIV-risky behaviors.[99-100] Rapid testing in county jails continues in NYS through other funding.

The AIDS Institute also undertook a comprehensive assessment of activities in relation to the Advancing HIV Prevention Initiative's four strategies (i.e., make HIV testing a routine part of medical care; implement new models for diagnosing HIV infections outside medical settings; prevent new infections by working with persons diagnosed with HIV and their partners; further decrease perinatal HIV transmission); including through a full-day staff retreat held at the University at Albany School of Public Health; and work group activities. Program models and materials were fine-tuned, as needed, to correspond with the four elements of national Initiative and front line health and human service providers were asked to emphasize the four strategies in their work.

On January 31, 2003, the US Department of Health and Human Services (DHHS) announced waived status for the OraQuick rapid test (a test using oral mucosal fluid), originally approved

as moderately complex.[227] This meant that the test could be used outside of traditional laboratories. Activities to implement rapid testing were conducted throughout 2003. Implementation of rapid testing in the ACT Program statewide, in community and correctional settings, began in May 2003, with regions phased in. There was full, statewide implementation by September. The AIDS Institute participated with NASTAD and with other state health departments in price negotiations with Abbott Laboratories and OraSure Technologies. Working with others in the Department, the AIDS Institute pursued authorization of Medicaid payment for same-day pre- and post-test counseling visits when rapid testing technology is used. Numerous training opportunities were developed and extensive resources pertaining to rapid testing were posted on the NYSDOH web site beginning in June 2003.

Also in 2003, the regulations that had been promulgated in 1999 for expedited testing in the delivery setting within 48 hours were amended to require a 12-hour turnaround time. This was in response to advances in testing technology that enabled a quicker turnaround time and information that demonstrated greater effectiveness of abbreviated regimens of ARV prophylaxis in preventing perinatal transmission if begun during labor or within 12 hours of the infant's birth.

Five HIV SNPs began enrolling members during mid 2003. Medicaid-eligible individuals had the option of enrolling in an HIV SNP, a mainstream managed care plan, or receiving services through the traditional fee-for-service system. Two of the five SNPs withdrew from the program in 2005, leaving three operational plans. Although SNP enrollment was lower than expected, HIV SNPs proved successful in engaging and retaining individuals in care, containing costs and achieving better health outcomes for their members.

Many families affected by HIV – sometimes across multiple generations – also experience poverty; chronic homelessness; substance use; domestic violence; mental illness; and family disruptions. In addition to health care concerns and emotional needs, families often need to address issues such as: custody arrangements; childcare; disclosure; elder care; and discrimination. In recognition, the AIDS Institute undertook a major resolicitation of funds supporting HIV prevention and health care services focused on women, children, adolescents and their families. Service models were significantly modified based on consumer and provider input obtained in 2002. New health care models were: Family-Centered Health Care Programs; Centers of Excellence in Pediatric HIV Care; and Youth-Oriented Health Care Programs. Family-Centered HIV Health Care Services, for example, established in 2003, coordinates HIV, primary care, and gynecologic services with a life cycle approach to caring for families. Multi-cultural, multidisciplinary teams integrate medical care, including HIV specialty care, with mental health; substance use; prevention with positives; case management; and other HIV-related services to address complex medical and social issues. This requires strong relationships among adult medicine; obstetric programs; and pediatric programs, including case managers, social workers, and child life specialists. Family-Centered HIV Health Care programs play a key role in reducing the risk of HIV perinatal transmission and provide comprehensive care for pregnant women with HIV.

A resolicitation of the "Permanency Planning" Initiative was also undertaken in 2003. With the evolving needs of families affected by HIV, the Initiative was renamed, "Families in Transition." Families in Transition provides supportive and legal services to stabilize and maintain families affected by HIV/AIDS, as well as to assist families in planning for the future care and custody of their children during parental illness and after the death of a parent.

Lastly, on December 12, 2003, the AIDS Institute hosted a Latino Forum in NYC to unveil the NASTAD report entitled, "Addressing HIV/AIDS: Latino Perspectives and Policy Recommendations."[228]

AIDS Institute staff participated on the Advisory Committee that guided the development of this report. The purpose of the Forum was to solicit community feedback regarding the report's policy recommendations. This activity targeted consumers; community-based providers; interested parties; and government representatives. The goals included introducing the document; addressing policy recommendations and strategies to address needs; and providing an update on NYS data pertaining to the HIV/AIDS epidemic in the Latino community.

AIDS Institute staff contributed to several other NASTAD policy statements focused on HIV/AIDS in communities of color. These have included "Why We Can't Wait: The Tipping Point Among African Americans and HIV/AIDS,"[229] released as an updated version of its 2001 African American Monograph on April 30, 2007; "Breaking Through the Silence: Key Issues and Recommendations to Address HIV/AIDS Among Asian Americans, Native Hawaiians, and Pacific Islanders in the United States,"[230] released in December 2007; two Native American Issue Briefs which were released in 2004 and in 2008;[231-232] and an overview of health departments' responses to HIV/AIDS among Native Americans.[233]

2004 AIDS Institute staff planned and conducted a daylong seminar titled, *"Health Literacy: A Missing Link in HIV Prevention,"* on March 19, 2004, funded in part by CDC. The seminar featured nationally recognized experts in the field of health literacy. More than 200 participants from across NYS were in attendance.

The AIDS Institute became increasingly involved in activities related to viral hepatitis during 2004. Staff collaborated with other Departmental programs on efforts to integrate viral hepatitis with HIV/AIDS, STD and other public health programs[234] and NYSDOH became nationally recognized for its hepatitis integration activities.[235-236] The OMD received a three-year grant from the CDC for a national project to develop, field test and disseminate a comprehensive, modular, skill-building training to serve as a national curriculum on viral hepatitis. NYSDOH staff compiled a list of experts in viral hepatitis to serve on a National Advisory Panel for the Viral Hepatitis Training Center. OMD physicians attended a meeting of the HIV Panel of the Medical Society of the State of New York to discuss rapid testing, hepatitis C and overdose prevention. Staff continued to develop the CDC-funded Viral Hepatitis Education and Training Cooperative Agreement and the HIV/HCV Co-Infection Project at Montefiore Medical Center (MMC) was launched to provide comprehensive and supportive services to co-infected patients in MMC's Infectious Disease clinic and community health centers. A five-year, "New York State Viral Hepatitis Strategic Plan," was published in June 2004.[237]

A group of 17 experts in the field of hepatitis C, HIV, and infectious disease was convened in September 2004 to develop NYSDOH clinical guidelines with regard to hepatitis C. The primary objective of the guidelines was to provide health care providers with guidelines for diagnosis, treatment, and management of patients infected with hepatitis C virus. The guidelines (containing four main sections: risk assessment and screening; diagnosis; treatment; medical management and prevention) were published and distributed to health care providers statewide and made available on-line.

On September 29, 2004, a meeting between NYSDOH and OASAS was held including OASAS Commissioner Gorman, Dr. Birkhead and NYSDOH staff. The agenda addressed topics of concern to both agencies, including: HIV services to substance users; hepatitis C services; tobacco cessation initiatives; improving coordination between providers serving active users and substance use treatment; rapid testing; and methamphetamine. Agreement was reached to enhance collaboration on a number of these projects.

Based on the national leadership on quality improvement in HIV care, the OMD was additionally funded by HRSA in 2004 to establish the National Quality Center (NQC). The mission of NQC is to advance the quality of care nationally for all people living with HIV/AIDS by providing state-of-the-art technical assistance on quality improvement to Ryan White grantees under all parts of the law. Technical assistance services include: dissemination of quality improvement resources; provision of face-to-face workshops; online training opportunities for HIV providers; training of training approaches; and on-site individualized technical assistance by experienced consultants. As of 2009, NQC had trained over 5,000 individuals on quality management via workshops; reached more than 4,000 HIV providers in more than 35 national technical assistance calls; graduated over 350 individuals in training of trainer activities; and developed an online training academy that has been accessed more than 10,000 times. NQC established itself as the premiere technical assistance center and reached more than 85% of all 561 federally funded Ryan White grantees.

2005 As people with HIV/AIDS lived longer thanks to effective antiretroviral regimens, there were increases in morbidity and mortality due to non-AIDS malignancies and other chronic conditions not necessarily related to HIV disease (e.g., cardiovascular diseases, diabetes, etc.). This led to an effort by the Institute to assess the prevalence of the most important modifiable risk factor for illness and death: tobacco use.[238] A statewide survey conducted in 2005 identified an extremely high rate of smoking among PLHWA who are in care in NYS: 59%. This rate is three times the rate of the general population of the state (currently at 18%). The same year, the one-day event, "Light Up Your Life: A Leadership Forum on HIV and Tobacco," was held at Rockefeller University in NYC to mobilize the HIV community to recognize and address this issue. Since 2005 the AIDS Institute has promoted the integration of smoking cessation within HIV prevention, health care and supportive services.

The AIDS Institute collaborated with DOCS to develop and distribute a discharge planning packet to inmates exiting state correctional facilities. This packet includes a general health and human service resource guide as well as prevention information on HIV; STDs and hepatitis C; and condoms. The discharge packets were distributed to approximately 26,000 inmates exiting State correctional facilities during 2005. Provision of the packets has continued and the contents have expanded to include additional materials.

On January 19, 2005, two HIV STOPS WITH ME campaigns were launched in NYS with a kick-off in NYC. One campaign covered NYC and neighboring counties; the other campaign was for Buffalo. Created in 2000 by Better World Advertising, a San Francisco-based social marketing firm, HIV STOPS WITH ME, now known as HIV STOPS WITH US, recruits and uses HIV-positive peers (spokesmodels) to promote prevention via positive messages presented in an authentic manner to other HIV-positive persons. The goals of the campaigns in NYS are to decrease HIV transmission and improve the health and well-being of people with HIV/AIDS by increasing the sense of community among HIV-positive individuals in order to facilitate behavior change and reduce transmission; empowering people living with HIV/AIDS to become active participants in efforts to halt the epidemic; linking HIV-positive persons to health care and supportive services; increasing the self-esteem of HIV-positive persons leading to care and concern for one's health and well-being; and reducing the stigma of living with HIV by portraying persons as responsible people who are leaders in HIV prevention efforts.

Later that month, the success of New York's efforts to prevent perinatal transmission received accolades in conjunction with the CDC's release of an *MMWR* article profiling reduction of perinatal HIV transmission.[239] *The New York Times* highlighted the success in NYS with several interviews of NYS-based providers and others, including AIDS Institute Director Dr. Guthrie S. Birkhead.[240]

In April 2005, changes in NYSDOH guidance were announced to reduce barriers to HIV counseling and testing; to promote entry into care; and to facilitate improved monitoring of HIV treatment and antiviral resistance in persons with HIV. Emergency regulations to implement new reporting requirements for laboratories became effective June 1, 2005. Informational presentations and materials were developed and distributed broadly to health and human service providers; local health departments; criminal justice providers; and others. A statewide satellite videoconference was also offered on July 13, 2005. NYS' testing guidance was highlighted by the CDC in a national broadcast that aired in November 2005.

Building on the lessons learned during the initial phase of ACT for Youth, in May 2005, NYSDOH released a competitive RFP totaling $2.05 million to further advance youth development strategies. One component supported community mobilization through local "Collaborations for Community Change" while the second component was for a single Center of Excellence with statewide youth development responsibilities. After another interdisciplinary, objective review process, awards were announced in January 2006 for 12 local collaborations and a Center of Excellence for the Integration of Youth Development and Adolescent Programs. The core team of NYSDOH managers who have guided ACT for Youth since its inception continue to provide guidance and oversight.

When more than 21,000 persons living with HIV/AIDS were displaced by Hurricane Katrina and ensuing levee failures in August 2005,[241] the AIDS Institute joined with federal agencies and other states to implement programs and policies to assure that persons with HIV infection who were displaced were assured care and services during their interim residence in NYS. In addition to clarifying emergency ADAP coverage, emergency Medicaid coverage was provided.

A two-day African-American HIV/AIDS Working Forum to Address Capacity Building Strategies, held in Poughkeepsie in October 2005, was attended by more than 200 people. The purpose was to provide an opportunity for discussion of the impact of HIV/AIDS in NYS among African-Americans and strategies to address the impact. The format selected for the Forum was that of a "mini focus group," with a cross section of attendees at each of 26 circular tables. Predetermined questions were used by trained facilitators to guide discussion. After responses were reviewed and analyzed, a report was published that described major and minor themes, together with background information about the Forum, and a summary of the participants' evaluations.[242] The Summary Report was also provided to attendees and others, so that their activities could be informed by the recommendations, and it was also made available on the NYSDOH public web site. Recommendations from the Forum have continued to guide the AIDS Institute. The importance of an effective response to HIV/AIDS in communities of color was again highlighted in the AIDS Advisory Council's report titled, "Women in Peril, HIV & AIDS: The Rising Toll on Women of Color," in December 2005.[175]

2006 Throughout 2005-2006, AIDS Institute staff fulfilled a leadership role in activities related to reauthorization of the Ryan White CARE Act. Staff kept the NYS Congressional delegation informed and participated with national organizations, such as NASTAD. There were frequent informational sessions and briefings, as well as local presentations to providers and consumers. Proposals from the administration and a few states charged that the epidemic had shifted away from the northeast and west, to the south. It called for resources to follow the epidemic. The AIDS Institute responded, demonstrating that in fact, the epidemic had not shifted and that these proposals attempted to level the playing field within existing appropriations through the distribution of funds in a manner that would harm thousands of persons living with HIV/AIDS in some jurisdictions. In Congress, there was a campaign against New York, and NYS was falsely charged

with being overfunded, funding "fluff" services, and misusing funds. Senator Clinton and Congressman Engel worked tirelessly to correct the record and ensure that persons living with HIV/AIDS in NYS were not harmed. During this period, NYS regularly made a compelling case about the need to increase the overall amount of resources rather than redirect resources from high-prevalence states to states with emerging needs. In December of 2006, a compromise was reached, and a bill was passed that limited reductions in resources and avoided severe disruptions in services. Still, NYS has lost approximately $14 million in Ryan White funds since the law was reauthorized in 2006.

Over the previous decade, NYS had developed a comprehensive approach to preventing mother-to-child HIV transmission (MTCT) that resulted in a significant decrease in perinatal transmission[243-244] from 10.9% (97 cases) in 1997 to 2.7% (16 cases) in 2003. The program had evolved to include surveillance; outreach to high-risk pregnant women; and education, training and support for those providing care for HIV-positive pregnant women, their exposed newborns and their infected infants. Perinatally-infected adolescents had also become another identified population with unique needs.[245] NYS regulations required that all women in prenatal care in regulated facilities receive HIV counseling with voluntary testing presented as a clinical recommendation. As a safety net, birth facilities are required to provide expedited testing in labor and delivery when the mother's HIV status is unknown on admission. As a result of these efforts, the prenatal HIV testing rate in NYS had risen from 64% in 1997 to 95% in 2003. In 2006, the AIDS Institute completed a study of 47 cases of residual MTCT occurring between January 1, 2002 and December 31, 2004. The findings suggested that the major factors associated with residual MTCT were inadequate prenatal care, lack of adherence to antiretroviral medications and acute HIV infection during pregnancy. Contributing factors included substance abuse, mental illness and homelessness.[246]

Effective November 1, 2006, the visit structure for the HIV Primary Care Medicaid Program was changed to: extend reimbursement to support HIV testing in hospital emergency departments; eliminate post-test counseling (negative) and drug and immunotherapy visits; and revise utilization markers for the HIV Counseling without Testing and HIV Counseling (Positive) visits.

Chapter 413 of the Laws of 2005 (amending Article 33 of the NYS Public Health Law effective April 1, 2006) authorized establishment of Opioid Overdose Prevention Programs and required a report to the Governor and the Legislature on the causes and extent of opioid overdose.[247] The Department turned to the AIDS Institute to implement this new initiative, in recognition of the Institute's experience and expertise serving injection drug users, through such programs as: harm reduction/syringe exchange; expanded syringe access; and co-located services for substance users. At this time, opioid overdose prevention programs were operational in a few areas of the US outside of NYS. They train nonmedical persons (laypersons) to perform rescue breathing and administer naloxone, an FDA-approved injectable medication, to another individual to prevent an opioid/heroin overdose from becoming fatal. Naloxone, also known as Narcan, is a prescription medicine that reverses an overdose by blocking heroin (or other opioids) in the brain for 30 to 90 minutes. After consultation with other jurisdictions which already had opioid overdose prevention programs (as well as with others) regulations were developed by AIDS Institute staff, in collaboration with other Departmental units. The regulations set forth requirements for prospective programs to register with the Department to obtain a certificate of approval. Emergency regulations were filed with the Secretary of State to take effect April 1. A half-day symposium regarding the new initiative which was held in NYC on April 19 attracted an overflow crowd.

Section 3381 of the NYS Public Health Law which had authorized the Expanded Syringe Access Demonstration Program (ESAP) from January 1, 2001 through March 31, 2003 had been extended

through September 1, 2007, following the results of an independent evaluation.[248] The extension of ESAP through 2007 had been provided by Chapter 16 of the Laws of 2003. By 2007, there were more than 3,000 ESAP-registered pharmacies, health care facilities and practitioners assuring ready access to syringes without prescriptions. ESAP providers were selling or furnishing two to three million nonprescription syringes a year and the need for broad access to syringes remained high in all areas of the state. In addition, more than 60 "alternative safe sharps collection sites" had been put into place at pharmacies, housing authority complexes, a community college, community-based organizations and public health clinics. More than 11,000 pounds (five and one half tons) of used sharps had been collected at more than 60 alternative sharps collection sites.[212] Chapter 58 of the Laws of 2006 reauthorized ESAP through September 1, 2011. ESAP was later made permanent in 2009 by Chapter 58 of the Laws of 2009.

Expanded laboratory reporting for enhanced epidemiologic surveillance of HIV/AIDS was implemented via regulatory amendments, effective July 14, 2006, which expanded laboratory test reporting to include results of viral load, CD-4 and HIV drug resistance testing.

A two-day Gay Men/MSM Forum held December 5-6, 2006, in Albany, brought together a broad range of gay men/MSM and individuals working with these populations. Such a forum had been recommended by an internal AIDS Institute Gay Men's Workgroup report developed in 2004 and revised in 2006, building upon the Gay Men/MSM Leadership Forum's 1998 report.[169] The 2006 Forum provided plenary presentations and engaged attendees in discussion groups. Recommendations, derived from structured discussion groups, addressed a broad range of policies and programs (e.g., stigma; youth; interventions for prevention; access to services; HIV testing; mental health; and training). The role of the Internet in HIV prevention received attention in the Forum and was beginning to receive greater attention from researchers and AIDS Institute staff.[249] A report about the Forum, including recommendations, was published in November 2007.[250]

2007 As a result of many interventions, by 2007, transmission from blood products was virtually unheard of in the US; mother-to-child transmission in the US had been reduced;[251] and the number of new HIV and hepatitis C infections among IDUs in the US had fallen precipitously, possibly more than 70%.[252-253] However, sexual transmission continued to account for an increasing proportion of new HIV infections, particularly in New York's most vulnerable populations. In 2007, young men of color who have sex with men and women of color, remain at heightened risk for sexually transmitted HIV.[254-255] Internal AIDS Institute planning meetings during 2006 focused on reducing sexual transmission among IDUs and, in 2007, this planning was broadened to encompass sexual risk reduction for all populations.

Based on NYS data and in concert with a 2006 CDC-revised recommendation for prenatal HIV testing, the Department developed a recommendation for a second prenatal HIV test in the third trimester of pregnancy. The AIDS Institute developed and widely disseminated a "Health Alert: Steps to Further Reduce Mother-to-Child HIV Transmission in New York State,"[256] highlighting important strategies to continue reducing MTCT. These strategies are: identifying acute HIV infection during pregnancy; repeat HIV testing in the third trimester; point-of-care rapid testing (with a one-hour turnaround time, if possible) in delivery settings, and assuring access to care and supportive services for HIV-positive pregnant/postpartum women.

Initiatives to promote HIV counseling and testing, for all populations, continued as rapid test technology continued to evolve. Rapid testing significantly altered the means by which persons could find out their serostatus. The percentage of clients receiving their results went from approximately 85% to 98% with most clients being provided their results in 20 minutes.

The AIDS Institute's Anonymous Counseling and Testing (ACT) Program gained invaluable experience implementing rapid testing.[257] As a result, the ACT Program played a crucial role in providing guidance and technical assistance to providers statewide with such success that adoption of rapid testing proceeded more quickly in NYS than in other areas of the country. More and more, AIDS Institute providers began to offer rapid testing technology as a strategy to increase HIV testing in primary care settings, address low post-test return rates and facilitate HIV testing in outreach settings. Most providers offered at least one option for rapid testing, with some offering more than one. In addition, Medicaid reimbursement for HIV counseling and testing using rapid testing technologies was extended to emergency departments of Designated AIDS Centers and other hospitals participating in the HIV primary care program.

In conjunction with the ACT for Youth annual conference, a Governor's Proclamation designated May 1, 2007 as "Youth Development Day" in New York State.[258] The State's First Lady and Commissioner of Health Richard Daines, who succeeded Dr. Novello in 2007, joined the conference to welcome attendees and present the Proclamation.

2007 marked the 15th anniversary of authorized syringe exchange programs (SEPs) in NYS. A public event, including Commissioner Daines, SEP representatives, dignitaries from public, private, academic and research organizations who worked to advance syringe exchange as an effective HIV prevention intervention and AIDS Institute staff, was held in NYC. SEP growth, from five authorized SEPs in 1992 to 17 in 2007, enrollment of more than 120,000 SEP participants and referrals to other health and human services was accompanied by dramatic decreases in HIV prevalence (from 54% in 1990 to 13%) and hepatitis C prevalence (from 90% to 63%) among IDUs in NYC.[252]

A joint meeting involving the Commissioners of Health and OASAS was held on September 17, 2007. The meeting reviewed highlights of ongoing collaboration between the NYSDOH and the OASAS in several program and policy areas, including: HIV/AIDS; hepatitis; tobacco cessation; and harm reduction. The meeting also provided a forum for discussion of new and emerging areas for enhanced collaboration.

In November 2007, Eliot Spitzer was elected Governor of NYS after serving for eight years as NYS attorney general. As Attorney General, he gained a national reputation for enforcing ethics in the public sector. In an election night speech, Governor-elect Spitzer's promise of change, beginning on Day One of his administration, heralded the commitment of the new administration to support programs and services, including those related to HIV/AIDS. Until his resignation from office in March 2008, Governor Spitzer and his administration actively supported increases in funding for HIV/AIDS. As NYS' new Governor, Former Lieutenant Governor David Paterson continued to provide funding and support for HIV/AIDS issues until a global economic crisis. Imposition of cost-cutting measures ultimately required steps by the AIDS Institute to reduce funding to contractors.

Also during November 2007, the Department's public health resources were brought together under a single umbrella, the Office of Public Health (OPH), to be directed by Dr. Birkhead. With 17 years experience in the AIDS Institute, most recently as the Executive Deputy Director, Humberto Cruz was selected to serve as Director of the AIDS Institute. A new AIDS Institute senior management structure was announced in November 2007.

The New York State Condom (NYSCondom) Program was created in 2007 to increase the availability of condoms to prevent the transmission of HIV and many other sexually transmitted diseases (STDs). Male and female condoms, when used correctly and consistently, are very effective in preventing the sexual transmission of these infections. NYSCondom uses the Internet

and the NYSDOH public web site to offer eligible organizations the ability to request free male and female condoms; personal lubricant; dental dams; and finger cots to be made available at no cost to sexually active individuals in their communities. NYSCondom encourages community partners to develop or refine strategies for effective local distribution of condoms; to promote the use of condoms, safer sex and sexual health; and to let the AIDS Institute know how it can improve this program. NYSCondom built on a less formalized program that began in the earliest days of the AIDS Institute. Through this program, the AIDS Institute directly provided condoms to contractors and, in some cases, supported them in their purchase of condoms. Within the first six months, the program was exceeding its goal of distributing five million condoms a year.

Chapter 571 of the Laws of 2007 amended the Criminal Procedure Law and the Public Health Law to require HIV testing of criminal defendants charged with felony sex offenses upon the request of the victim/survivor. The amendments, effective November 1, 2007, were intended to help guide medical treatment of survivors. The OMD led development of this new program, convening an AIDS Institute work group that met with public and private sector stakeholders to discuss implementation and to facilitate intergovernmental collaboration and coordination with community-based domestic violence organizations. The OMD Medical Care Criteria Committee formulated clinical guidance. Educational materials for the survivor, the defendant and the legal system were developed and a statewide satellite videoconference was held.[259]

The OMD successfully built and sustained capacity for quality management for ambulatory care HIV programs in NYS and the US. Based on this, the OMD was funded to adapt HIVQUAL to build capacity for quality management internationally. HIVQUAL International was launched in Thailand in 2003. The HIVQUAL-T experience has demonstrated that HIVQUAL can be successfully adapted from one country to another, adjusting for differences in guidelines, resources, and health care models. By adjusting its model for quality management for international application, (together with staff from Ministries of Health and U.S. Government partners) HIVQUAL International has adapted the three basic components of quality management – performance measurement, quality improvement and quality program infrastructure – into unique national models that can be integrated and sustained with existing national quality management activities to meet the goals of national AIDS programs. Currently, HIVQUAL International offers consultation to countries that are supported by the President's Emergency Plan for AIDS Relief (PEPFAR). At present, additional countries have sponsored HIVQUAL International: Mozambique, Uganda, Nigeria, Haiti, Guyana, Namibia, and Kenya.

The HIV Education and Training Programs was awarded a five-year grant from the CDC to provide technical assistance to Adult Viral Hepatitis Prevention Coordinators (AVHPC) across the US. The purpose of this grant was to strengthen programmatic capacity and support the activities of AVHPCs. AVHPCs work to improve the delivery of viral hepatitis prevention services in health care settings and public health programs. The AIDS Institute was also awarded five-year funding from CDC to establish and maintain an Adult Viral Hepatitis Prevention Program. This funding replaced the previous funding received by the NYSDOH to maintain a Hepatitis C Coordinator position which had been located within the Center for Community Health (CCH) but was relocated to the AIDS Institute. With the new funding, the activities of the Hepatitis C Coordinator were expanded to include hepatitis A and B prevention activities and the title of the position became Viral Hepatitis Coordinator. The AIDS Institute provides leadership for some viral hepatitis program development activities while the surveillance, disease control and epidemiologic leadership rests within CCH.

Significant federal, state, and local resources were being directed to the design and development of electronic health records (EHRs) and systems for electronic health information exchange (HIE).

To assure input from HIV/AIDS consumers and providers, the AIDS Institute distributed a letter with a link to a document on the NYSDOH website. The letter sought public comment on policies and guidelines for consumer consent for the electronic exchange of personal health information. The Institute also held a series of focus groups with consumers and providers. The NYSDOH-convened Health Information Security and Privacy Collaborative (HISPC) held three stakeholder meetings to build a consensus on how patient consent would work. The meetings were attended by two representatives from the AIDS Institute and two consumers from the HIV/AIDS community. The AIDS Institute summarized input from focus groups and conference calls so that policies under development could benefit from recommendations from the HIV/AIDS community. The Institute also wanted to realize potential health care benefits for HIV-infected persons. The majority of consumers and providers supported EHRs/HIE. They also agreed with the potential benefits if the following were addressed: confidentiality; security; various operational issues to make the system safe and secure; comprehensive education about the process; and legal protections, with strong penalties for breaches. The overwhelming majority of consumers they consulted supported an affirmative written consent process which allows consumers to determine whether providers can access their EHR and, if so, which ones.

As noted previously, NYS has led the nation in providing specialized care for Medicaid recipients, with HIV/AIDS, in a managed care setting through creation and implementation of HIV Special Needs Medicaid Managed Care Plans. As of August 2007, more than 2,500 individuals were enrolled in this innovative program. In addition, more than 20,000 uninsured and underinsured New Yorkers living with HIV/AIDS received lifesaving medications and comprehensive health care services through the HIV Uninsured Care Programs. Comprehensive case management services were provided under the Community Follow-up Program to more than 14,000 HIV-positive persons through 53 programs located in regions throughout NYS. The number of programs providing transitional case management (TCM) services for active drug users who are interested in "transitioning" from active use to addiction treatment and recovery increased from five to seven. The percentage of successful TCM referrals for in-patient detoxification was 88 percent – 78 percent for ambulatory detox; 85 percent for methadone maintenance treatment; 84 percent for drug- free residential treatment; and 72 percent for buprenorphine treatment.

Beginning in late 2007, reform of NYS' health care reimbursement system took a major step forward. The 2008-09 NYS budget initiated a multi-year process of transitioning funding from inpatient to outpatient services to support quality care in outpatient settings and address the problem of avoidable hospitalizations. Concurrent with the outpatient investment, a new rate-setting methodology, Ambulatory Patient Groups (APGs), was selected to replace the flat "per-visit" outpatient payment methodology for providers licensed and services provided under Article 28 of the PHL. Under APGs, the amount that is paid for a visit would vary depending on the intensity of the services provided during the visit. Implementation of APGs would be phased in to allow for a transition period. The AIDS Institute was required to address numerous policy implications for HIV care in this transition, including: support for the organizational infrastructure of DACs; HIV case management; quality of care reporting; application of utilization thresholds; the carving out of laboratory resistance testing; and future Medicaid data collection.

Federal funding cuts also required attention in late 2007 to early 2008; the FY 2008 federal Labor-HHS-Education appropriations bill proposed an across-the-board rescission that would result in cuts to both the CDC HIV Prevention Cooperative Agreement and Ryan White funding. These compound funding reductions, together with staff target reductions, made it difficult for the AIDS Institute to address current workload and to take on new unfunded mandates.

2008
Completing and Commemorating a Quarter Century of the Fight Against HIV/AIDS in NYS

This section summarizes activities throughout calendar year 2008, during which time the AIDS Institute reached its 25th year milestone, including:

- *Conduct of eight regional Listening Forums across the state, each of which was comprised of three separate Listening Forum sessions (one for clinicians, one for consumers, one for nonclinical health and human service providers) that were attended by more than 500 individuals.*
- *Launch of initial components of a comprehensive, statewide response to hepatitis C.*
- *Response to ongoing health care reform efforts with implications for the HIV/AIDS service delivery system.*
- *Continued refinement of programs and services, including release of updated standards for DACs reflective of the complexity of HIV/AIDS care and the changing health care environment.*
- *Commemoration activities that recognized the AIDS Institute's creation 25 years ago, (effective July 30, 1983) that captured the accomplishments of the AIDS Institute, as well as those of the Interagency Task Force on HIV/AIDS and the AIDS Advisory Council.*

2008 In January 2008, Mr. Cruz, convened staff to convey 21 priority objectives, drawn largely from AIDS Institutewide strategic planning activities ongoing since 2006. The strategic planning goals and objectives also offered a framework for development of measurable goals and objectives to assess program performance and plan for the future. As part of the AIDS Institute's ongoing commitment to community collaboration as the epidemic evolved, plans were developed for statewide regional "Listening Forums" to provide an opportunity for the AIDS Institute to reach out to the community to solicit input and recommendations regarding issues and concerns for which the AIDS Institute has responsibility. Regional meetings attended by more than 500 consumers, clinical and nonclinical providers and were held throughout the state between June and October. Issues raised included: fiscal concerns related to Medicaid reform; managed care for persons with HIV/AIDS; counseling and testing concerns; case management needs and service reductions; hepatitis C; unique needs of infected and affected adolescents; immigrant populations' needs and concerns; transportation; lack of affordable housing; lack of physician specialists; and syringe access needs.

With growing awareness of the extent of hepatitis C and the need for a comprehensive response to hepatitis C,[237, 260] a budget request developed by AIDS Institute and Center for Community Health (CCH) staff resulted in the first-ever appropriation of NYS funds specifically for hepatitis C. Although a bill to create a Hepatitis C Advisory Council (modeled after the AIDS Advisory Council), was vetoed, the Governor asked the Department to convene such a body. The newly formed Hepatitis C Advisory Council was convened for the first time on March 2, 2008. The purpose of the Council is to advise the Department on the development and implementation of a comprehensive hepatitis C program. The initial meeting focused on Council member self-introductions, sharing of their perceptions about hepatitis C, an orientation to NYSDOH hepatitis C programs and plans for updating the NYS Five-Year Viral Hepatitis Strategic Plan, published in 2004.[237] Prior to the

meeting, Council members joined Commissioner Daines, patient advocates, legislators and others for a press event in the Legislative Office Building that focused on the newly formed Council and hepatitis C.

Implementation of sweeping recommendations issued by the Commission on Health Care Facilities in the 21st Century (also known as the Berger Commission) to restructure the hospital and nursing home systems in NYS and reduce excess capacity affected two DAC hospitals, St. Vincent's Hospital in Manhattan and Cabrini Medical Center. Several other DAC hospitals were also closed due to the economic downturn. AIDS Institute staff intervened to assure continuity of care for patients at risk for interruption in their HIV treatment regimens due to several of these hospital closures.

Even to this day, academic programs that prepare social workers, counselors, other human service professionals, nurses and physicians have not adequately incorporated information about HIV in their curricula. It is common that a person who earns an advanced degree in social work or counseling may not have received formal training in HIV. As a result, the AIDS Institute's efforts at making professional training programs available to both clinicians and nonclinicians remain essential. In 2008, the AIDS Institute's training initiative for non-clinicians educated over 10,000 providers annually in 45 different training curriculum delivered over approximately 500 training days. Similarly, the Clinical Education Initiative had grown to train more than 8,000 clinicians annually on critical issues in HIV care.

In April 2008, over 200 persons from throughout NYS attended the second, statewide, HIV and faith communities forum, "Responding to the Call." The forum provided opportunities to learn and to share information about resources available to faith communities and faith-based HIV prevention activities. Participants engaged in an interfaith dialogue on issues that continue to challenge HIV prevention and health care efforts (e.g., sexuality, stigma, discrimination) and heard about collaborative efforts to strengthen the capacity of faith communities to partner and to respond to HIV/AIDS.

In its budget deliberations, the NYS Legislature recognized the important role of HIV/AIDS research by including language requiring the AIDS Advisory Council to prepare a report on the potential for developing an HIV/AIDS research initiative. The report was submitted to the Department, the Legislature and the Governor. An appropriation of $125,000 to support work related to such an initiative was also authorized.

In 2008, updated standards for the DACs were released. The new standards reflected the programmatic and organizational complexities of providing high quality HIV/AIDS care in the evolving health care environment. With the shift of HIV health care from an acute to a chronic disease model, integrated primary care and preventive services with subspecialty care for disease conditions associated with aging and long-term ARV therapy, were needed. In addition, the financial environment for hospitals had changed, with Medicaid Managed Care, including HIV Special Needs Plans, having become primary payors. The DAC model evolved to meet the needs of the patient by providing a primary care home for persons with HIV. Enhanced coordination with community-based partners to identify patients at risk, to help patients access and remain in care, and to understand and adhere to their complicated regimens was reflected. There was an emphasis on developing integrated care networks that encompass community-based providers. These providers offered COBRA case management. It also included service agencies funded by Ryan White, Medicaid Managed Care Plans (including HIV SNPs, adult day care, treatment education and adherence programs). It was critical to use health information technology's enhanced capacity to identify and reach those persons in the community most at risk for HIV and not yet diagnosed.

Medicaid restructuring continued to require attention. AIDS Institute staff sought to understand the impact of APGs on the HIV/AIDS service delivery system.[261] Internal discussions were also held with the Office of Health Insurance Programs regarding the manner in which Medicaid recipients with HIV/AIDS receive health care. On July 30, 2008, a conference call was held for AIDS Advisory Council members regarding the possible removal of the exemption of Medicaid recipients with HIV/AIDS from mandatory enrollment in managed care. This issue had been under consideration since 1994. Existing options included fee-for-service care (including at DACs), HIV SNPs (for those in NYC), and mainstream Medicaid managed care plans. Consideration was being given to removal of the exemption for individuals in NYC, where SNPs would be an option. The following week, on August 1, 2008, the Department issued three press releases: "'Choices in Care' Ranks HIV Care in Special Needs Managed Care Plans as Superior to Traditional Medicaid,""DOH Reports on 2007 Health Plan Performance," and "Comparison of Fee-for-Service, Mainstream Managed Care and HIV Special Needs Plans (SNPs) Shows Better Quality in Managed Care."[262-264] Overall, HIV SNP enrollees were reported to have better health results than those in fee-for-service. An ongoing collaboration involving the Memorial Sloan Kettering Cancer Center, the Albert Einstein College of Medicine and the AIDS Institute has continued to explore the needs and concerns of persons with HIV/AIDS to make care as responsive and effective as possible.[265-267]

Some community members responded with allegations that the removal of the exemption was being considered, "...simply to save the state money...not a good argument for managed care."[267] and that the "...study justifying mandatory HMO enrollment for HIV-positive Medicaid recipients [was] deeply flawed."[268] On September 3, 2008, the AIDS Institute and Office of Medicaid Management held a stakeholders meeting in NYC. Outside, protesters held signs saying, "Don't force people with AIDS into substandard care." Mr. Cruz invited to the meeting those protesters who were willing to protest quietly.

In August 2008, Governor Paterson proposed a $2.6 billion saving plan and called an emergency session of the NYS Legislature.[269] Agreement was reached on savings for the then current year of more than $400 million, on top of a hiring freeze and more than $630 million in cuts to current year spending.[270] In early September, the Governor directed NYS agencies to submit budget requests for the 2009-2010 fiscal year that kept spending to the 2008-2009 limits.[2719] HIV/AIDS providers reacted, saying that the result would be dismantling of safety net services, "...in a haphazard way at a time when there are more people living with AIDS than ever in our state."[272] Later that month, the collapse or takeover of some of Wall Street's biggest financial institutions led to a financial crisis that exacerbated the state's budget deficit. Governor Paterson instituted further measures to cut costs and assure that only necessary expenditures would be made. AIDS Institute-funded providers shouldered cuts, like all NYS-funded entities. Steps were taken to notify all AIDS Institute-funded providers of reduced contract amounts for 2008-2009.

Overview of 25-Year Commemoration Activities During 2008 On January 15, as noted above, the AIDS Institute's Director, Mr. Cruz, convened staff to convey 21 priority objectives, drawn largely from the AIDS Institute's strategic planning activities which had been in process since 2006. He also noted the AIDS Institute's 25-year milestone, indicating that 2008 would be a year of commemoration. In April 2008, the *DOH Insider* featured an interview with Mr. Cruz titled, "The AI Mission: Put an End to the HIV/AIDS Epidemic – Person by Person, Day by Day." On July 7, staff were provided several versions of a 25-year commemoration logo for the AIDS Institute and invited to select the final logo. Results of staff votes were tallied and, on August 4, thanks were extended to all who participated in the selection of the AIDS Institute's 25 Year Commemoration Logo. Copies of this logo, together with instructions, were made available on the AIDS Institute's

Intranet. In addition, a generic version of the 25-Year Commemoration Logo was prepared as the AIDS Institute's official logo. An informal AIDS Institute staff potluck luncheon was held on July 22 to commemorate the 25-year milestone. The luncheon was held simultaneously, via video teleconference technology, in Albany, Menands, New York City and Buffalo. It featured a Moment of Silence, remarks from Mr. Cruz, food and camaraderie, a quiz (with prizes), and reflections from staff at each location who had been with the AIDS Institute the longest.

July 30th marked the 25th year anniversary of the signing of the legislation that created the Department's AIDS Institute and the AIDS Advisory Council. Governor David Paterson issued Proclamations marking the day. One pronounced July 30, 2008 as "AIDS Institute Recognition Day," and the other recognized the AIDS Advisory Council, also created effective July 30, 1983. On August 1, the *DOH Insider* again recognized the AIDS Institute in an article titled, "25 Years of Working to Defeat AIDS: Governor Issues Proclamations for AIDS Institute and Advisory Council."

The September 11 AIDS Advisory Council meeting included an agenda item dedicated to recognizing the Council for its 25 years of services. Each Council member received a signed Proclamation. Council members and others shared their reflections on the role of the Council over the years and those present were provided with a commemorative packet titled, "New York State AIDS Advisory Council: Honoring 25 Years of Service, 1983-2008."[14]

The last of a series of AIDS Institute Regional Listening Forums were held on October 29-30 in New York City. The Regional Listening Forums were initiated by Humberto Cruz, Director of the AIDS Institute, in conjunction with the AIDS Institute's Strategic Planning and the 25-year milestone, to continue the Institute's longstanding commitment to maintaining a dialogue with consumers and providers. Each Regional Listening Forum provided for separate discussions with clinicians, with consumers and with community-based providers. In each Listening Forum, Mr. Cruz acknowledged the 25-year commemoration of the AIDS Institute, thanking staff, community members and providers for their support of, and collaboration with, the Institute over the years. Although much has been accomplished by working side-by-side, much remains to be done. On behalf of the AIDS Institute, Mr. Cruz reaffirmed the AIDS Institute's long commitment to partnership with the community and providers.

On November 6, staff were invited to visit a new AIDS Institute 25th Year Commemoration web page on the AIDS Institute's Intranet. The 25th Year Commemoration web page provided a brief background about the creation of the AIDS Institute 25 years ago, in 1983. The 25th Year Commemoration web page offered links to existing information pertaining to the AIDS Institute, such as, "About the AIDS Institute,"as well as new materials developed during 2008, such as 25-year commemoration milestones (Appendix II), that highlighted the AIDS Institute's accomplishments. Similarly, links to AIDS Advisory Council materials, including a 25-year commemoration packet honoring the Council's work, were included. Additional features continue to be added.

December 1, 2008 marked the 20th official observance of World AIDS Day. AIDS Memorial Quilt panels were displayed in the Empire State Plaza Convention Center from December 1 through December 4. The AIDS Institute used the AIDS Memorial Quilt as an educational tool to provide HIV prevention education to as many young people as possible and to raise awareness of the HIV/AIDS epidemic. On December 2nd, individuals and organizations from across the state were honored for their work in the field of HIV/AIDS. In his opening remarks, Commissioner Daines recognized the AIDS Institute's 25-year history. He pointed out achievements under the leadership of Dr. Birkhead and Mr. Cruz. Dr. Daines noted the regional Listening Forums, completed in October, which will further inform the AIDS Institute's strategic planning. He was followed by Dr. Birkhead and

Mr. Cruz, both of whom echoed Dr. Daines' appreciation for the work of AIDS Institute staff and of the Institute's many partners, including consumers and providers.

Mr. Cruz further acknowledged the AIDS Institute's 25-year history at a December 9 staff meeting. He noted his observation the previous week that the AIDS Memorial Quilt panels demonstrated a sharp decline in deaths beginning in the mid-1990s. Mr. Cruz reminded staff that, while the AIDS Institute has accomplished much, its work must continue. He thanked those present for their continued commitment to the fight against HIV/AIDS and indicated his plans to continue the discussion at an AIDS Institute full staff meeting (the fourth ever), to be held in early 2009. A compendium of staff-authored publications that was completed in early 2009 (Appendix 3) is available in electronic form on the AIDS Institute Intranet.

Current Status and Future Directions

When creating the AIDS Institute, the NYS Legislature and Governor showed great foresight about the need for a comprehensive response. As noted previously, in 1987, Commissioner of Health Dr. David Axelrod recognized that, "AIDS is a life-threatening disease for which there is still no cure, no vaccine, no immediate symptoms to warn of infection, and no way to accurately predict how many people infected with the virus will become ill." (Axelrod, D. February 19, 1987). Despite impressive progress over the intervening years in NYS and beyond, there is still no cure or vaccine. More recently, in 2008, the extent, complexities and impact of the HIV/AIDS epidemic has been referred to as, "one of the defining features of the past quarter of a century."[273]

On December 1, 2008, the 20th anniversary of World AIDS Day, it was estimated that, worldwide during 2007, there were 33 million people living with HIV; 2.7 million new HIV infections and two million AIDS-related deaths.[274] As of December 1, 2008, approximately 116,000 New Yorkers were reported living with either HIV or AIDS and NYS remained the epicenter of the AIDS epidemic, with 16 percent of all people living with AIDS nationally. The 25th year milestone provided the AIDS Institute an opportunity to reflect on its past and to look forward, renewing its strong commitment to providing necessary leadership for HIV/AIDS program and policy development in NYS.

The continuum of prevention, care and supportive services needs constant attention. It must evolve to accommodate new needs, medical advances and technologies and must be adapted to changes in the larger health care delivery system, including reimbursement, electronic medical records and other factors. All of the major HIV/AIDS service delivery reimbursement structures and standards that have been put into place over the years have evolved. That they still exist today is a testimony to the vision and dedication of AIDS Institute staff and others who helped build the continuum. Many are still evolving in conjunction with reimbursement and health care reform efforts currently underway.

Opportunities to integrate HIV/AIDS programs and services with those for other diseases and conditions are ongoing. New challenges require new approaches and insights. Some of the challenges include: the aging of the HIV epidemic;[275-277] the role of HIV in diseases other than AIDS;[278] and issues faced by perinatally-infected young people as they enter adulthood. The need for basic HIV/AIDS education and other established mainstays of the state's response is ongoing. The HIV/AIDS epidemic still rests in a larger societal context, with sociocultural, demographic, economic, political and other influences. Fear, stigma, discrimination, health care inequities, poverty, trauma, rejection of populations at high risk and the fact that the epidemic is largely driven by sexual activity and illicit drug use continue to pose profound challenges in the efforts against HIV/AIDS. As noted by CDC Director Dr. Julie Gerberding during her September 16, 2008 testimony before the Oversight and Government Reform Committee, US House of Representatives, "AIDS is a social disease as well as a viral disease. . . if we don't address the underpinning issues, we'll never get to where we need to be."[279]

Twenty-five years later, maintaining a comprehensive response for NYS will continue to require the full, priority attention of the AIDS Institute and its many partners. The AIDS Institute remains a vital component of the state's infrastructure for a comprehensive response to HIV/AIDS. The AIDS Institute's Strategic Plan Framework (Appendix 4), reflective of the regional "Listening Forums," illustrates the array of issues that will be the focus of the AIDS Institute's efforts, in partnership with others, in the months and years ahead.

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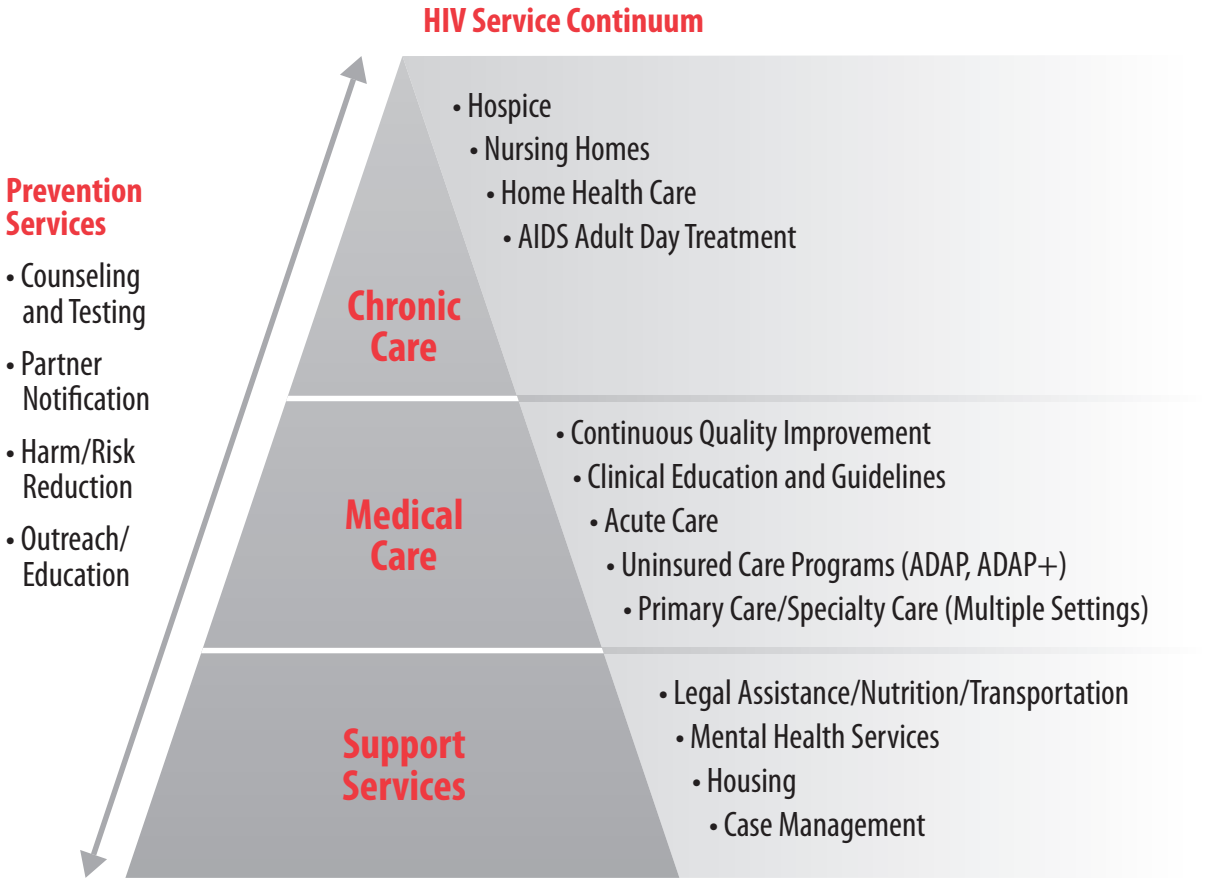
Figure 1
New York State HIV/AIDS Service Delivery Continuum



Appendix 1
AIDS Institute Directors, Brief Biographical Notes: 1983-2008

Melvin L. Rosen, M.S.W., AIDS Institute Director, 1983-1987 Beginning in 1982, Mr. Melvin Rosen served as the first Executive Director of Gay Men's Health Crisis in New York City (NYC). He fulfilled a leadership role in mobilizing public and private responses to HIV/AIDS in NYC and beyond, including assisting the World Health Organization in establishing a subcommittee on AIDS. Mr. Rosen was the Director of the AIDS Institute from 1983 through 1987. He received a master's degree in social work in 1983 from Hunter College. In 1987, he became Deputy Director for Special Programs and Regulatory Affairs at the Helen Hayes Hospital in West Haverstraw, New York.

Nicholas A. Rango, M.D., AIDS Institute Director, 1987-1993 Dr. Nicholas Rango received his M.D. degree from Northwestern University in 1970 and completed his clinical training in Internal Medicine at Cook County Hospital in 1973. As a recipient of a Robert Wood Johnson Clinical Scholarship at Columbia Presbyterian Medical Center from 1975 through 1978, he pursued graduate studies in sociology with Professor Robert K. Merton. From 1978 to 1987, he held the Samuel R. Milbank Chair in Health and Society at Barnard College of Columbia University. Immediately prior to joining the AIDS Institute, Dr. Rango was Executive Director of the Village Nursing Home, a 200-bed proprietary facility located in NYC. Dr. Rango served as the Director of the AIDS Institute from 1987 until his death in 1993.

Nilsa Gutierrez, M.D., AIDS Institute Director, 1994-1995 Dr. Nilsa Gutierrez joined the AIDS Institute as a medical consultant in 1989, serving as Associate Medical Director. Dr. Gutierrez became the Medical Director of the AIDS Institute in 1992, a position that she held until 1994, when she became the Director of the AIDS Institute. Dr. Gutierrez served as Director of the AIDS Institute until her resignation in 1995. Dr. Gutierrez had been an instructor in Clinical Medicine at Columbia University School of Medicine and an Attending Physician with Harlem Hospital's Primary Care Network. Dr. Gutierrez was an advocate for women's health, as well as minority health. Dr. Gutierrez was appointed to the National Commission on AIDS Task Force on HIV Infection Among Hispanics in 1991 and was later invited to serve on the Presidential Advisory Council on HIV/AIDS.

Guthrie S. Birkhead, M.D., M.P.H., AIDS Institute Director, 1995-1996 (Acting), 1995-2007 Dr. Guthrie S. Birkhead was a graduate of CDC's Epidemic Intelligence Service and Preventive Medicine Residency Programs, was Board Certified in Internal Medicine and Preventive Medicine and held a Master's Degree in Public Health. He had joined the Department in1988, had become Director of the Bureau of Communicable Disease Control in 1993 and was Associate Professor at the School of Public Health at the State University of New York at Albany. He was also President of the Council of State and Territorial Epidemiologists. Dr. Birkhead served as Director of the AIDS Institute until his appointment as Deputy Commissioner, Office of Public Health in 2007.

Humberto Cruz, M.S., AIDS Institute Director, 2007-Present Mr. Cruz joined the AIDS Institute as Deputy Director, NYC Affairs, in February 1990. In October, 1990, he became the Director of the Division of HIV Health Care and in 2004 he became Executive Deputy Director. A native of Puerto Rico, he held Master's Degrees in Planning and in Human Resource Development. He had eight years of experience in substance abuse treatment, including as Director of Human Resource Development at Promesa, Inc. in NYC and as Director of Criminal Justice Programs at OASAS (then DSAS). An openly gay, HIV-positive man, Mr. Cruz was nationally known as a leader in HIV/AIDS when he was chosen to succeed Dr. Birkhead as Director of the AIDS Institute.

Appendix 2
AIDS Institute Milestones: 1983-2008

1981

Pneumocystis carinii pneumonia (PCP) diagnosed in gay men in Los Angeles

"Rare Cancer" (Kaposi's sarcoma or KS) diagnosed in gay men in New York City

First PCP diagnosed in injection drug users (IDUs)

First woman with AIDS in the US

First Pediatric AIDS Case in the US

Centers for Disease Control and Prevention (CDC) declares the new disease an epidemic

1982

Gay Men's Health Crisis (GMHC) established

First Haitian refugee with AIDS

First hemophiliac with AIDS

1983

New York State Department of Health (NYSDOH) AIDS Institute established

NYSDOH AIDS Advisory Council (AAC) established

NYSDOH AIDS Research Council established

Executive Order # 15 by Governor Cuomo created Interagency Task Force on AIDS (IATF)

1984

Community Service Programs (CSPs)

1985

Designated AIDS Centers (DACs)

Anonymous HIV Counseling and Testing (ACT) Program

1986

"AIDS Impact on Public Policy, An International Forum: Policy, Politics and AIDS"

AIDS Intervention Management System (AIMS)

Medical Care Criteria Committee

HIV Clinical Guidelines Program

1987

AIDS Drug Assistance Program (ADAP)

Blinded HIV Testing of Newborns

IDU cases surpass gay men/men who have sex with men (MSM) cases in NYS

Executive Order #99 by Governor Cuomo expanded the IATF

HIV Seroprevalence Studies

"AIDS Does Not Discriminate" Social Marketing Campaign

First Clinical Guideline Printed

First "AIDS in NYS" Published

1988

Article 27-F HIV Confidentiality Law

Community-Based organization Initiative

Maternal/Pediatric Program

Chronic Care Initiatives

Supported Housing Programs

HIV/AIDS Materials Initiative

Committee for the Care of Children and Adolescents with HIV

Prevention Surveys and Evaluation Unit (now Office of Program Evaluation & Research)

1989

"AIDS; New York's Response, a 5-Year Interagency Plan"

Expanded DAC regulations for specialized care of infants, children, adolescents and pregnant women

HIV Primary Care Programs (in community health center and substance abuse treatment settings)

Anonymous HIV Counseling & Testing and Education in Prisons

HIV Clinical Education Program

HIV Clinical Scholars Program

1990

Obstetrical Initiative

Medical Protocols 1st Edition

Community Follow-Up Program

Prison Project

Legal Services Initiative

Formal Memorandum of Understanding (MOU) with NYS Department of Correctional Services

Nutrition Programs

Case Management Services

1st Statewide HIV/AIDS Conference

1991

Informed Health Care Worker Policy

Ryan White Title II HIV CARE Networks

Pediatric/Adolescent Care Guidelines published

AIDS Day Care Program expansion

AIDS Home Care Program

Enhanced Fees for Physicians

Transportation Services

Criminal Justice Initiative

2nd Statewide HIV/AIDS Conference

Office of Information Resources (now Information Systems Office)

1992

ADAP Plus

Medical Protocols 2nd Edition

Syringe Exchange Regulations filed and programs approved

Multiple Service Agencies (MSAs) and Community Development Initiative (CDI)

Women's Supportive Services

HIV Quality of Care Program

Dental Standards of Care Committee

3rd Statewide HIV/AIDS Conference

Contract Management System (CMS)

First Meeting of NASTAD (National Alliance of State and Territorial AIDS Directors)

1993

Newborn Testing Bill introduced

Adolescent Initiative

AAC Subcommittee on Newborn Testing

Uniform Reporting Project

4th Statewide HIV/AIDS Conference

1994

Statewide AIDS Service Delivery Consortium (SASDC)

NYS HIV Prevention Planning Group (PPG)

Peer Initiative

Lesbian, Gay, Bisexual & Transgender (LGBT) Initiative

Prevention Services for Adolescents & Young Adults

Clinical Guidelines for Adults and for Children and Adolescents

First Version of Uniform Reporting System (URS)

5th Statewide HIV/AIDS Conference

1995

Permanency Planning Initiative

Pediatric HIV Diagnostic Testing Service

Pediatric Clinical Guideline

Perinatal Transmission Clinical Guideline

Best Practices – Occupational Post-Exposure Prophylaxis (PEP)

National HIVQUAL Project funded

HIV/AIDS Instructional Guide, Grades K-12

1996

Families in Crisis Report

Newborn Testing Legislation

Prenatal Counseling & Recommended Testing

Consented Release of Newborn HIV Test Results

ACT Program in county correctional facilities (jails)

Anonymous to confidential test conversion option in ACT Program

Clinical Guideline for HIV Prevention

Persons Living with HIV/AIDS Leadership Training Institute (LTI)

6th Statewide HIV/AIDS Conference

1997

Comprehensive Newborn HIV Screening Program

Maternal-Pediatric HIV Prevention and Care Program

Chautauqua County HIV exposure incident

Gay Men/MSM Leadership Forum

Waiver for HIV Special Needs Managed Care Plans (SNPs)

OraSure Testing introduced by ACT Program

Best Practices – Sexual Assault

HIV/QUAL Project

Executive Order #54 by Governor Pataki reestablished and expanded the IATF

7th Statewide HIV/AIDS Conference

1998

HIV Quality of Care Advisory Committee

Physicians' Prevention Advisory Committee

Treatment Adherence Initiative

HIV Reporting and Partner Notification Law

8th Statewide HIV/AIDS Conference

1999

CDC/Health Resources and Services Administration (HRSA) funded Criminal Justice Demonstration Project

HIV Welfare to Work Pilot

Expedited testing (48 hours) in delivery settings

2000

ADAP Plus Insurance Continuation (APIC) Program

HIV Names Reporting & Partner Notification Law implemented

Families in Transition Act

Expanded Syringe Access Demonstration Program (ESAP) Legislation

Community Action for Prenatal Care (CAPC)

Prenatal Care Provider Training

Mental Health Initiative

Assets Coming Together (ACT) for Youth

IATF Report to the Governor

First Statewide Performance Report

9th Statewide HIV/AIDS Conference

2001

Project War Against the Virus Escalating (WAVE)

Faith Community Project and "Meeting on Common Ground" Faith Forum

Mental Health Guidelines Committee

Clinical Guideline for Mental Health Care

Oral Health Clinical Guideline

Best Practices – Adherence

ESAP Implemented

2002

Intensive Outreach to Young, Gay Men of Color

Transitional Case Management in Harm Reduction and Substance Abuse Initiative Programs

Consumer Advisory Council

Committee for the Care of Women with HIV Infection

Pharmacy Advisory Committee

Antiretroviral (ARV) Therapy Clinical Guideline

1st Statewide Hepatitis C Conference

Second NYS HIV performance data report

2003

Rapid Testing in ACT Program piloted and implemented statewide in community sites and county correctional settings (jails)

Expedited testing (12 hours) in delivery settings

Authorization of Medicaid for same-day pre- and post-test counseling

Rapid HIV testing in hospital Emergency Departments (EDs)

HIV SNP Enrollment

Family-Centered Health Care Services

Prevention Services for Women

Youth Health Care Programs

HIVQUAL International

ESAP Reauthorization

Committee for the Care of the HIV-Infected Substance User

New Case Management Guidelines

2nd Statewide Hepatitis C Conference

Families in Transition

Latino Forum

2004

Prevention for Positives Campaign

Increase in Number of Women's Programs Integrating HIV Rapid Testing

MSM workgroup recommends prevention & care needs of gay men/MSM

Best Practices – Oral Health

Making Sure Your HIV Care Is the Best It Can Be – Consumer Training

National Quality Center funded

3rd Statewide Hepatitis C Conference

NYS Viral Hepatitis Strategic Plan

2005

"HIV STOPS WITH ME" Prevention With Positives Campaign (now called "HIV STOPS WITH US")

HIV Counseling and Testing Guidance

African American HIV/AIDS Working Forum

4th Statewide Hepatitis C Conference

2006

Maternal-Pediatric Residual Transmission Study

Recertification of all HIV Primary Care Program Providers

HIV Counseling & Testing Medicaid Rate Extended to Emergency Departments

ESAP Reauthorization

Opioid Overdose Prevention Program

Gay Men/MSM Forum

International Quality Improvement Work

2007

15th Anniversary of Syringe Exchange in NYS

Condom Access Program

Plan for Enhanced Sexual Risk Reduction

AIDS Institute Reporting System (AIRS)

Health Alert Regarding 2nd Test in 3rd Trimester

Defendant Testing Program

Best Practices – GYN Care

5th Statewide Hepatitis C Conference

International Quality Center – HQ International

2008

DAC Standards Redesigned with Enhanced Focus on Integrated Care Networks and Patient Retention

Hepatitis C Advisory Council

Young Adult Consumer Advisory Council

"Responding to the Call" Faith Forum

Regional Listening Forums with Consumers and Providers

6th Statewide Hepatitis C Conference

Governor Proclamations Recognizing the AIDS Institute and the AIDS Advisory Council

Appendix 3
Staff-Authored Publications: 1983-2008

Journal articles, letters to the editor, books, book chapters published during 1983-2008:

1986

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1989

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1992

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1993

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1995

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Tesoriero JM, Sorin MD, Burrows KA, LaChance-McCullough ML. Harnessing the heightened public awareness of celebrity HIV disclosures: "Magic" and "Cookie" Johnson and HIV testing. *AIDS Educ Prev.* 1995; 7(3): 232-250.

1996

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1997

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1998

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Appendix 4
Strategic Plan Framework: July 7, 2009

Innovative and Effective Organization

Goal 1

Meet the needs of a dynamic and diverse population through organizational effectiveness and innovation.

Objectives

1.1 Effectively respond to new trends and challenges through innovative mechanisms that best meet the needs of diverse populations.

1.2 Promote opportunities for staff development that encourage professional growth, support promotion and improve overall functioning.

1.3 Maximize communication within the AIDS Institute and with external parties to facilitate knowledge sharing, and improve program effectiveness.

1.4 Maximize available resources by streamlining AIDS Institute staff, functions and programs.

1.5 Sustain existing and attract new resources.

1.6 Continue efforts to hire qualified staff at all levels who are reflective of the communities most impacted and who are culturally competent.

1.7 Monitor and manage contracts in a manner that is efficient for providers and effective for the AIDS Institute and that assures that regulatory, grant and contract requirements are met.

Data and Science-Driven Programs and Policies

Goal 2

Effectively use data and science to assess programs, develop new initiatives and target resources.

Objectives

2.1 Manage resources and develop programs on the basis of scientific evidence and objective data.

2.2 Use data to target care and services and identify facilitators and barriers to care.

2.3 Improve utilization of internal and external data for program development, evaluation and monitoring.

2.4 Streamline, standardize and integrate information systems to promote data sharing within the AIDS Institute, with other NYSDOH offices and with other parties to facilitate planning and evaluation.

2.5 Communicate research findings internally and externally to promote program development and ongoing improvement.

2.6 Assure and promote the use of data collected by the AIDS Institute by providers, advisory bodies and others.

Access to Care

Goal 3

Provide early access to, and maximize utilization of, all services available under the AIDS service continuum.

Objectives

3.1 Assure that all persons living with HIV/AIDS have health coverage that promotes access to and retention in care.

3.2 Increase the number of persons diagnosed early in the course of their disease; improve linkages with care, timely entrance into and retention in care.

3.3 Engage hard to reach populations through collaboration with non-traditional providers and community stakeholders.

3.4 Improve integration of health and social support services with input of external and internal partners.

3.5 Improve access to services for persons with identified needs (homelessness, mental illness, substance use, individuals who are deaf and hard of hearing, etc.).

3.6 Effectively utilize reimbursement mechanisms to encourage development of proficient health care services.

3.7 Minimize disparities in access to and retention in care.

3.8 Improve access to specialty and subspecialty services inclusive of HIV specialists, dental and mental health care and substance use treatment.

3.9 Assure that health delivery systems promote access to quality care and evolve to meet emerging needs.

3.10 Assure provision of supportive services necessary to ensure access to and retention in care.

Quality

Goal 4

Provide quality care, prevention and supportive services to improve the health and well-being of persons living with HIV and AIDS.

Objectives

4.1 Improve quality of care through evidence-based practices.

4.2 Create and disseminate best practice standards and policies for HIV care, treatment, prevention and support services.

4.3 Assure that providers have the resources, tools and education necessary to measure and monitor quality of care, develop their own quality programs and promote performance-based outcomes measurement.

4.4 Promote provider and consumer involvement in the development of and adherence to guidelines.

4.5 Use quality improvement strategies to implement change.

4.6 Regularly review quality programs to assure responsiveness to changing environments.

Prevention

Goal 5

Prevent new infections and maintain health of those infected.

Objectives

5.1 Increase the number of persons who know their HIV/STD status. Increase testing both within the health care system and among persons who do not access the health care system through expanded integration with providers of other health services.

5.2 Collaborate with health care and community-based providers to reach populations at risk.

5.3 Continue availability of comprehensive HIV education including knowledge of risk/harm reduction strategies.

5.4 Promote evidence-based prevention approaches including increased use of condoms and sterile injection equipment.

5.5 Promote secondary prevention programs such as, but not limited to, prevention of disease progression and prevention of opportunistic infections. Promote prevention of primary transmission.

5.6 Target prevention programs and services using data and statistics and develop new strategies to reach diverse populations.

Leadership

Goal 6

Advocate and lead in consultation with state, local and community-based organizations and with persons living with and at risk for HIV and AIDS.

Objectives

6.1 Coordinate the state's policies with respect to HIV and AIDS.

6.2 Use policy research and science to guide program development and implementation.

6.3 Propose, participate in and influence state, local and national HIV policy.

6.4 Work with staff, providers, consumers, community members and elected officials on policy issues.

6.5 Provide leadership to reduce stigma and discrimination associated with HIV/AIDS.

6.6 Support and promote community leadership.

6.7 Raise community awareness of policies and proposals that impact providers and persons living with HIV and AIDS in NYS.

6.8 Promote leadership internally and externally (e.g., mentoring, internships, Leadership Training Institute).

6.9 Learn from and include consumers and other relevant parties in HIV program development.

Mission

The AIDS Institute provides leadership to alleviate the human toll of the HIV/AIDS epidemic through programs, policies and partnerships that exemplify compassion and empower individuals, communities and institutions.

Vision

Guided by science and innovation, community input and compassion, the AIDS Institute strives to:

- Eliminate new HIV infections;
- Ensure early diagnosis and ongoing access to quality care, support and treatment for all infected;
- Provide support for those affected; and,
- Eradicate stigma, discrimination and disparities in health outcomes.

Strategic Plan Framework

The AIDS Institute's Strategic Plan Framework reflects the results of an internal strategic planning process and was informed by the views and perspectives shared by providers and consumers at a series of "Listening Forums" conducted during June through October 2008.

Notes

Notes

State of New York
Department of Health

7/10