

AIDS Institute Successes and Challenges

Responding to an Evolving Epidemic

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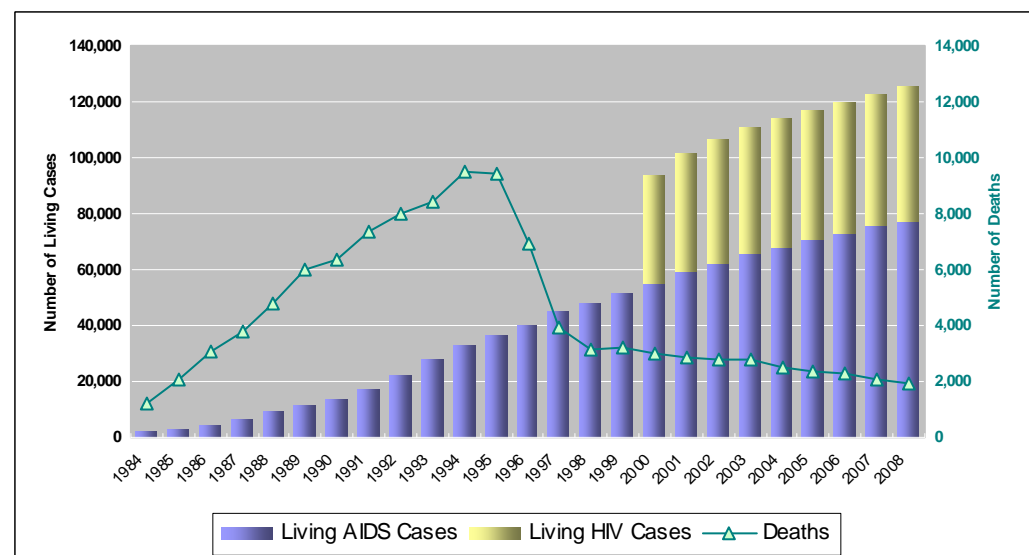
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Key Successes

In its 27-year history, the AIDS Institute has provided leadership in New York State, at the national level, and internationally. A foundation of the AIDS Institute's strategy – and one of its primary strengths – is a commitment to working with and obtaining input from persons infected and affected by the epidemic and providers to inform the development of policies and programs. Working with its partners, the AIDS Institute has responded to a myriad of challenges and has developed the concept of a comprehensive continuum of prevention, care and supportive services. Key successes include:

- Reduction of newly diagnosed AIDS cases by 73% between 1993 and 2008
- Reduction in deaths among persons living with HIV/AIDS by 80% between 1994 and 2008
- Reduction of newly diagnosed HIV cases by 25% between 2002 and 2008
- Reduction in the proportion of newly diagnosed cases among injection drug users from 52% in 1992 (new AIDS cases) to 6% in 2009 (all newly diagnosed HIV cases)
- Reduction in mother-to-child transmission of HIV from 25-40% in 1990 to 2.1% in 2009
- HIV Uninsured Care Programs provide access to life-saving medical services and medications to more than 23,000 uninsured and underinsured New Yorkers living with HIV/AIDS annually
- Cost-containing HIV Special Needs Plans reduced Medicaid costs by \$4.2 million in 2008 alone and retained patients in care and improved health outcomes for more than 10,000 enrollees in 2010
- Integration with STD services to reduce sexual transmission of HIV and STDs and to better serve the clients of both programs
- Integration with hepatitis services to raise public awareness, promote prevention and treatment in primary care settings, and target injection drug users for hepatitis C screening and hepatitis B vaccination
- In 2010, the HIV Testing Law expanded HIV testing to reach all persons aged 13 to 64 receiving hospital or primary care services. The law also facilitates entry into care for HIV-positive persons
- National and international leadership in ensuring high quality of HIV care and continual quality improvement through the development of the National Quality Center, HIVQUAL-US, and HIVQUAL-International

Trends in Living AIDS/HIV Cases and Deaths, 1984 to 2008



In its 27-year history, the AIDS Institute has provided leadership in New York State, at the national level, and internationally

The AIDS Institute's policies and programs have evolved in response to shifts in demographics, changes in the clinical profile of the HIV epidemic, advances in technology and scientific breakthroughs, and alterations in the environment

Introduction

New York State (NYS) is the epicenter of the HIV epidemic in the United States. While the majority of cases are from New York City (NYC), all of the other 57 counties have reported cases. Even if NYC cases are excluded, NYS ranks seventh in terms of living AIDS cases nationally. New York State has both urban and rural epidemics, and since all of the populations affected by HIV/AIDS live in NYS, there are actually many epidemics within its

borders. There is no population or age group in NYS that has not been touched by HIV. In December 2009 there were about 129,000 people diagnosed with HIV/AIDS living in NYS. It is estimated that an additional 30,000 or more persons are infected, but are unaware of their status. Seventy-eight percent of persons living with HIV/AIDS in NYS are persons of color.

About the AIDS Institute

Establishment and Continuing Mission

The AIDS Institute was created within the New York State Department of Health (NYSDOH) in 1983, establishing the organizational public health and health care infrastructure needed to support a comprehensive response to an emerging crisis. Public Health Law Article 27-E specifies the AIDS Institute's responsibilities, powers and duties. Well established within the Department of Health, the AIDS Institute is one of four centers in NYSDOH's Office of Public Health. The AIDS Institute strives to eliminate new HIV infections; ensure early diagnosis and ongoing access to quality care, support and treatment for all infected New Yorkers; provide support for those affected; and eradicate stigma, discrimination, and disparities in health outcomes. In recognition of the synergy among HIV, sexually transmitted diseases (STDs), and viral hepatitis, an organizational realignment within the Department has integrated HIV, STD, and hepatitis services within the AIDS Institute in order to improve prevention efforts and health outcomes. Further broadening its mission, the realignment also brought responsibility for HIV/AIDS and STD surveillance to the AIDS Institute.

Accomplishments over the Years

The AIDS Institute's achievements in fighting the epidemic and serving those infected are notable and include the development of financing mechanisms and client-centered service programs that serve as national models. The AIDS Institute has established an HIV/AIDS service delivery system that is unmatched in the nation. The continuum of HIV/AIDS services that has been developed in NYS includes HIV prevention, education, outreach, health care, and a range of support services, as well as medications and assistance with insurance continuation. The continuum is operationalized through service contracts, Medicaid-supported services, and HIV care programs for the uninsured and underinsured administered through funding pools (e.g., AIDS Drug Assistance Program). From its beginnings, the AIDS Institute promoted and

established the concept of a medical home for persons living with HIV/AIDS. The AIDS Institute supports the service delivery system by providing education, training and technical assistance to providers and monitoring the quality of services delivered. These programs have resulted in the near elimination of perinatal transmission of HIV and dramatic reductions in new infections among injection drug users, in the number of newly diagnosed cases, and in deaths among persons with HIV/AIDS. People with AIDS are now healthier and more able to be productive members of NYS society. Statistics show the success of both prevention and care programs, though they have opposite effects on the epidemiological data. Due to the success of primary and secondary prevention, the number of new diagnoses continues to decrease markedly. At the same time, the number of persons living with HIV and AIDS continues to increase due to successful care and treatment that have dramatically reduced the number of deaths and have kept people living longer, healthier lives.

Timely Responses to a Rapidly Changing Epidemic

The nature and scope of the HIV epidemic has changed rapidly and radically. The AIDS Institute has been and continues to be called upon to shift direction, change focus, and accommodate ever-increasing numbers of people and communities in need. The increasing magnitude and complexity of the epidemic have broadened the scope of responsibility of the AIDS Institute and intensified its leadership role in the formulation of State and national policy and in the rapid development and implementation of services to meet existing and emerging needs. The AIDS Institute's policies and programs have evolved in response to shifts in demographics, changes in the clinical profile of the HIV epidemic, advances in technology and scientific breakthroughs, and alterations in the environment. Resources have been shifted, programs have been modified or eliminated, and new strategies have been adopted to effectively target services to meet

About the AIDS Institute (continued)

the needs of at-risk, infected and affected populations, including improvements in access to treatments for mental health, substance use, and other co-morbidities affecting large proportions of HIV-infected persons in NYS.

Enhanced Organizational Capabilities and Efficiency

Once a disease-specific entity focused primarily on HIV prevention and care, the AIDS Institute’s mission has expanded to incorporate STD and hepatitis prevention and treatment. The AIDS Institute’s responsibility has also broadened to incorporate HIV and STD surveillance. In addition, as HIV has become a chronic disease and infected persons live longer, they are experiencing other medical problems related to the aging process, long-term side effects of medications, and other co-morbidities such as hepatitis, tuberculosis, STDs, cancer, heart disease, hypertension, diabetes, cognitive problems, osteoporosis, and mental illness. As a result, program models have been and will continue to be modified to incorporate prevention and treatment for co-occurring conditions.

Community Partnerships

The AIDS Institute places a priority on community input and has established effective partnerships – with persons infected and affected, providers, community leaders, advocacy groups, research entities, and other federal, state, and local government agencies – to inform the development of policies and programs. In fact, one of the hallmarks of the AIDS Institute’s strategy is ongoing dialog with consumers as well as the community-

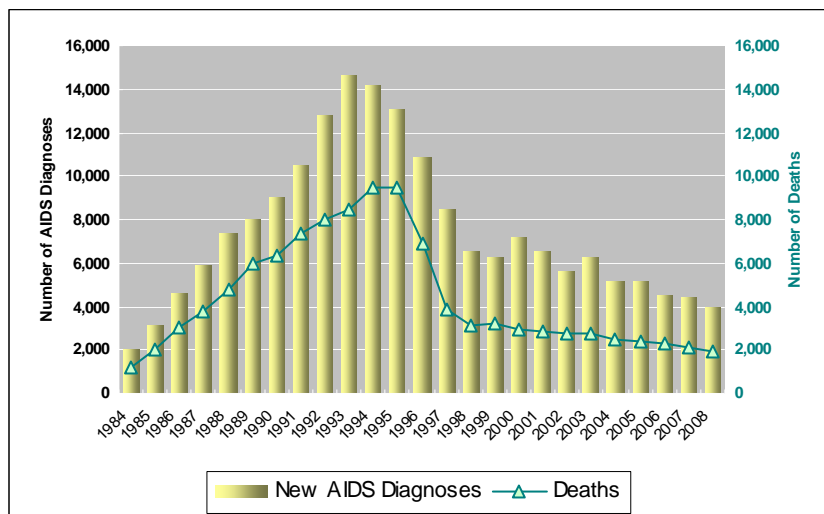
based health and human service providers on the front lines. Other principles associated with the AIDS Institute’s approach include targeting services to meet the needs of all populations, providing the support services that persons with HIV/AIDS need to engage and stay in care, innovative service delivery and financing systems, incorporating prevention – both primary and secondary – throughout the continuum of services, ensuring the quality of services delivered and adherence to standards of care, and providing leadership.

National Leadership

The AIDS Institute’s leadership role extends beyond NYS. The AIDS Institute’s Director is a member of the Presidential Advisory Council on HIV/AIDS (PACHA) and an executive committee member of the National Alliance of State and Territorial AIDS Directors (NASTAD). As such, the AIDS Institute has taken an active role in deliberating HIV/AIDS policy at the national level, in the context of both prevention and care, including discussions with federal partners, other states, and Congress. For example, the AIDS Institute was an active participant in developing the White House Office of National AIDS Policy’s (ONAP) National HIV/AIDS Strategy, having had experience in the development of a strategic HIV/AIDS plan for NYS years prior to ONAP’s call for a national strategy. In addition, the AIDS Institute serves as the National Quality Center, providing technical assistance on quality improvement to HIV/AIDS service providers throughout the nation and internationally. Further, AIDS Institute staff have been called on to present at national meetings and to offer technical assistance to other states.

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Reduction in Newly Diagnosed AIDS Cases and Deaths

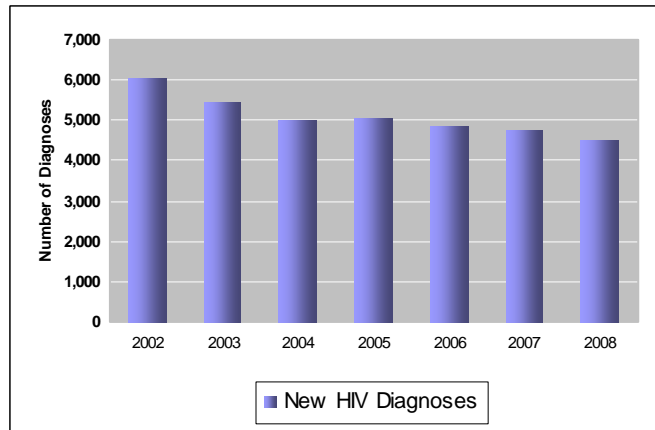


The AIDS Institute’s prevention, education and care programs have made innovative interventions and effective antiretroviral therapy available to those in need, thus leading to a dramatic decline in newly diagnosed AIDS cases. In 1993, there were 14,577 newly diagnosed AIDS cases. In 2008, there were 3,911 newly diagnosed AIDS cases – a reduction of 73%.

The availability of comprehensive health care and life-saving medications in NYS has led to a dramatic reduction in deaths among persons living with HIV/AIDS. Deaths among persons living with HIV/AIDS declined by 80% between 1994 (9,480 deaths) and 2008 (1,938 deaths).

Reduction in Newly Diagnosed HIV Cases

There has been a 25% decline in new HIV diagnoses* between 2002 (6,047 cases), and 2008 (4,524 cases). Numbers of new diagnoses have decreased among Blacks, Hispanics and Whites, in women of all ages, and in men of all ages except those ages 13-24.



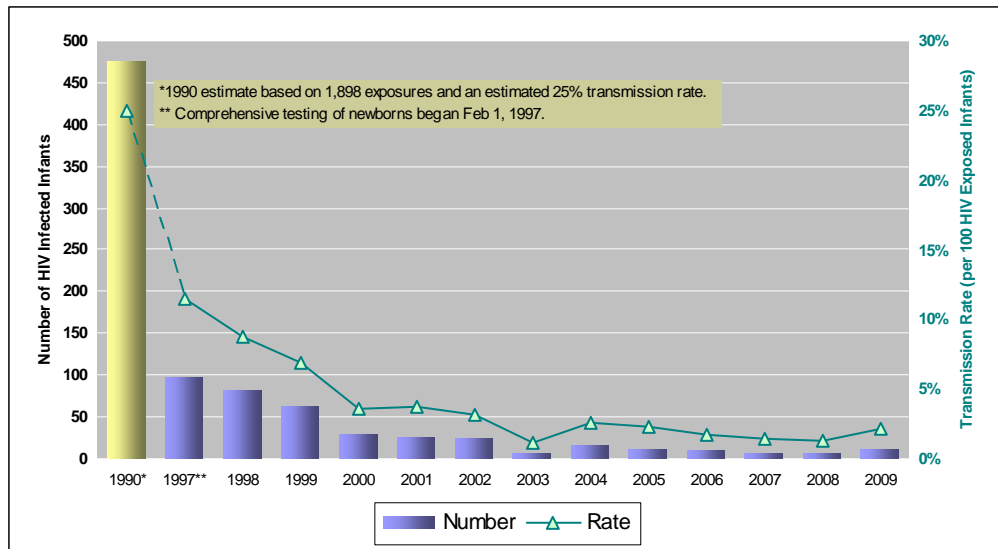
*Regardless of concurrent or subsequent AIDS diagnosis

In 2010, only 3 cases of mother-to-child transmission of HIV have been documented, suggesting that NYS has the potential to reach CDC's definition of elimination of mother-to-child transmission

Reduction in Mother-to-Child Transmission of HIV

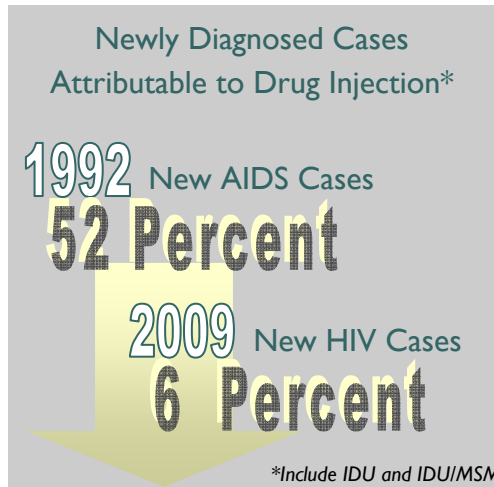
The AIDS Institute has developed a comprehensive approach to preventing mother-to-child transmission (MTCT) of HIV. The strategy involves surveillance; outreach to high-risk pregnant women; extensive education and support for those providing care for HIV-positive pregnant women, their exposed newborns and their infected infants; technical assistance for all birth facilities; a regulatory requirement that all women in prenatal care in regulated facilities receive HIV counseling with voluntary testing as a clinical recommendation; expedited testing in labor and delivery when the mother's HIV status is unknown on admission, with the results delivered to the woman within 12 hours; and routine newborn screening as a safety net. It should be noted that New York is the only state to offer state-of-the-art diagnostic testing for all exposed infants. This overall strategy has led to an

increase in the prenatal testing rate from 64% in 1997 to 95% by 2002, which has remained at 95% to 96%. In addition, the percentage of mothers receiving prenatal antiretroviral (ARV) therapy has increased from 64.4% in 1997 to 93.7% in 2008, and rates of newborn receipt of ARV therapy have increased from 61.9% in 1997 to 99.7% in 2008. Further, there has been a decline in the rate of perinatal HIV transmission, estimated at 25% to 40% in 1990 (estimated 475 to 760 infected infants), to 11.5% in 1997 (99 infected infants) when newborn screening began, to 2.1% (11 cases) in 2009 – a reduction of 91.6% to 94.8% since 1990. To date in 2010, only three cases of mother-to-child transmission have been documented, suggesting that the State has the potential to reach CDC's definition of elimination of mother-to-child transmission (i.e., a transmission rate of < 1%).



Reduction in New Infections Among Drug Users

In the late 1980s and early 1990s, the epidemic in NYS was driven by substance use. In 1992, the Commissioner of Health was given regulatory authority to approve syringe exchange programs (SEPs). In 2000, the Expanded Syringe Access Program (ESAP) was established, augmenting harm reduction efforts for injection drug users by adding pharmacy sales and provision of syringes by health care professionals and also establishing safe sharps disposal programs throughout NYS. Recently, peer-delivered syringe exchange was approved as a new model of exchange after documented success as a pilot program, and a new State law was enacted adding language to the penal law to make it explicit that a person is not criminally liable for possessing syringes and drug residue in or on syringes that the person may legally possess based on his or her participation in the SEP or ESAP. Currently, there are 19 SEPs that furnish more than two million sterile syringes per year and more than 3,200 ESAP-registered providers. Syringe access in NYS has yielded impressive results. There has



been a dramatic reduction in the proportion of new cases among injection drug users*, from 52% in 1992 (new AIDS cases) to 6% in 2009 (all newly diagnosed HIV cases).

*Includes IDU and IDU/MSM

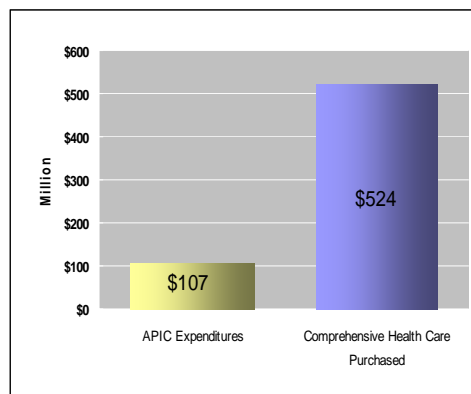
New York's HIV Uninsured Care Programs bridge the gap between Medicaid coverage and private insurance, providing universal access to medications and care for New York's residents living with HIV/AIDS

Life-Saving HIV Uninsured Care Programs

New York State HIV Uninsured Care Programs are the most comprehensive for uninsured HIV/AIDS care in the nation. The programs bridge the gap between Medicaid coverage and private insurance, providing universal access to medications and care for New York's residents living with HIV/AIDS. The AIDS Institute has established four program components for New Yorkers living with HIV/AIDS who are uninsured or underinsured with the aim to provide access to medical services and medications for the uninsured and underinsured in order to improve their health and quality of life. The AIDS Drug Assistance Program (ADAP) provides life-saving medications; ADAP Plus provides HIV primary care services; the Home Care Program provides care in the home; and the ADAP Plus Insurance Continuation (APIC) program provides assistance in paying health insurance premiums and offers comprehensive coverage in a cost-effective manner. The programs are funded through partnerships between NYS and federal governments and between NYS and NYC, Long Island, Lower Hudson, and Dutchess County Ryan White regions. The ADAP component provides access to more than 480 medications. Through ADAP Plus, more than 84,000 primary care visits were paid for in 2009-2010. More than 23,000 uninsured and underinsured New Yorkers living

with HIV/AIDS are served through the programs annually. Since inception, the programs have served more than 84,000 people. The APIC program has increased access to comprehensive insurance coverage for more than 5,500 people and has grown by 98% since 2005. In 2010-11, APIC anticipates purchasing more than \$122 million in comprehensive medical goods and services for more than 3,000 participants through program outlays of \$27.5 million.

APIC Return on Investment, 2002-2010



**Statewide
quality of care
program
standards
ensure that the
best clinical
care is provided
to patients
throughout
New York State
by improving
systems of care
delivery and by
stimulating
quality
monitoring**

Quality of Care

The AIDS Institute is committed to promoting, monitoring, and improving the quality of HIV clinical services for people with HIV in NYS. The Office of the Medical Director coordinates quality improvement activities including the development and dissemination of state-of-the-art clinical practice guidelines, measurement of clinical performance indicators derived from practice guidelines, onsite quality of care reviews, promotion of quality improvement activities, peer learning opportunities for providers, and consultations to support onsite quality improvement efforts. Groups of stakeholders participate in accomplishing these tasks. They include committees of clinical experts and expert HIV/AIDS service providers, consumer quality committees, and an internal quality work group. Statewide quality of care program standards have been developed that apply to all facilities providing HIV health care, 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.

All HIV programs throughout NYS are expected to self-report their annual quality of care performance data using standardized submission tools and methodologies. In recent years, 174 out of 184 (95%) HIV programs have submitted their performance data based on a review of 11,131 medical records. The remaining ten sites have been reviewed by an external review agency. In 2010, a secure website that meets all confidentiality concerns has been finalized for routine self-reporting of facility-level performance data. There have been general improvements in several areas, including: TB screening; viral load testing rates; appropriate management of ARV therapy; substance-use screening rates; tobacco-use screening rates; Mycobacterium Avium Complex (MAC) prophylaxis rates for indicated patients; dental exam rates; and hepatitis C screening rates.

The AIDS Institute's quality management efforts extend beyond NYS. The AIDS Institute was selected by the U.S. Health Resources and Services Administration (HRSA) to develop and implement the National Quality Center (NQC) to serve as the primary national resource for quality improvement and quality management in HIV care. Since its inception in 2004, NQC has provided leadership and support in quality improvement for Ryan White-funded grantees nationwide. The aim of this national initiative is to build among grantees across all Ryan White funding sources the capacity to improve the quality of HIV/AIDS care and services in the United States. The NQC partners with the AIDS Institute for Healthcare Improvement and experts with knowledge of HIV/AIDS quality management to provide state-of-the-art technical assistance and consultative services.

Based on the experiences in NYS, a HIVQUAL model has been developed for onsite quality improvement consultation to improve the quality of care delivered to persons with HIV to assist ambulatory care programs in NYS, in Ryan White-funded programs across the country through HIVQUAL-US, and in President's Emergency Plan for AIDS Relief (PEPFAR) focus countries through HIVQUAL International. The HIVQUAL-US Program is a partnership between the AIDS Institute and HRSA, which has the primary goal of building capacity and capability for quality improvement among Ryan White grantees throughout the nation. Internationally, the program offers consultation for capacity development for countries supported by PEPFAR who wish to establish a national quality management program and quality management programs in their HIV ambulatory clinics, including Thailand, Uganda, Mozambique, and Namibia. Built upon the principles of quality improvement and models developed through New York's HIV Quality of Care Program, this program guides HIV providers to build sustainable quality management programs.

Retention in Care

The AIDS Institute's Quality of Care Program has conducted a statewide campaign to build capacity for retaining patients in care. A three-year study of one-visit patients at over 150 HIV primary care sites offers insight on reasons why patients are not maintained in care. Several facilities have used the information from the study to develop quality improvement activities that zero in on those

patients not retained in care and develop strategies to improve retention of these patients. Learning networks have engaged providers in quality improvement projects to increase retention. The AIDS Institute has conducted workshops and video conferences to build capacity for improving patient retention in HIV primary care.

Health Literacy

The AIDS Institute's Quality of Care Program has implemented a major initiative over the last three years to build capacity among HIV providers to screen patients for health literacy and provide appropriate interventions. The AIDS Institute has also worked to build capacity among providers for screening the health literacy environment of facilities where HIV care is provided. Areas of the health literacy environment focused upon in the capacity building effort include literature, medication labels, and signage. Additional areas of focus include how providers communicate lab results,

HIV education, treatment strategies and medication needs. Quality improvement activities have been conducted in learning networks facilitated by the Quality of Care Program giving providers from across NYS the opportunity to learn and improve together. The monthly HIVQUAL workshop series has offered workshops on quality improvement activities to improve health literacy screening and interventions. The Quality Advisory Committee and Consumer Advisory Committee have developed a quality indicator to measure the rate of health literacy screening in NYS.

Expanded HIV Testing

In 2010, the New York State HIV-testing law was amended making significant changes to HIV testing practices in NYS. This law was enacted to increase HIV testing in NYS and promote HIV-positive persons entering into treatment. The legislation is critical since approximately 20% of HIV-positive New Yorkers are unaware of their infection status, and 33% of persons newly identified with HIV are diagnosed with AIDS within one year. Key provisions of the new legislation include: (1) HIV testing must be offered to all persons between the ages of 13 and 64 receiving hospital or primary care services with limited exceptions noted in the law. The offering must be made to inpatients, persons seeking services in emergency departments, persons receiving primary care as an outpatient at a clinic or from a physician, physician assistant, nurse practitioner or midwife. (2) Consent for HIV testing can be part of a general durable consent to

medical care, though specific opt-out language for HIV testing must be included. Consent for rapid HIV testing can be oral and noted in the medical record. (3) Prior to being asked to consent to HIV testing, patients must be provided information about HIV as required by the Public Health Law. (4) Health care and other HIV test providers authorizing HIV testing must arrange an appointment for medical care for persons confirmed positive. The AIDS Institute has held stakeholder meetings throughout NYS to obtain input on the implementation of the law and the development of regulations. To date, more than 500 stakeholders have attended these meetings. The AIDS Institute is in the process of developing regulations and continues to provide technical assistance to providers.

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Hepatitis

The AIDS Institute is responsible for coordinating the Department of Health's response to viral hepatitis and for hepatitis prevention and treatment programs. The AIDS Institute coordinated the NYS Viral Hepatitis Strategic Plan, launched state public awareness campaigns on hepatitis C (HCV), hosts annual hepatitis C conferences, and serves as the National Viral Hepatitis Technical Assistance Center, which supports the 55 state and large city Adult Viral Hepatitis Prevention Coordinators. In 2010, funds were awarded to 13 new programs to integrate HCV care and treatment in primary care settings for those mono-infected with HCV and those co-infected

with HIV and HCV. Most people with HCV do not know they are infected. With advances in HCV screening and treatment on the horizon, it is expected that the number of people living with HCV and aware of their diagnoses will increase. In order to better understand the current and future burden of disease in NYS, as well as health care-related costs, the AIDS Institute has undertaken a project to estimate the burden of disease for HCV in NYS. The project will include estimates and trends in incidence, prevalence, morbidity, mortality and health care-associated costs. The results of this project will better inform policy, planning and cost allocation in the future.

**HIV SNP
enrollees have
fewer inpatient
admissions and
shorter lengths
of stay,
resulting in
lower costs per
admission ...
it was estimated
that the HIV
SNP program
reduced
Medicaid
expenditures by
\$4.2 million
during calendar
year 2008**

Integration with Surveillance and STD Services

HIV and STD integration have been part of clinical practice since the early 1990s, leading to a dramatic decrease in syphilis incidence. Beginning in 2007, integration among NYSDOH field staff and in community-based organizations has been emphasized to address the continued sexual transmission of HIV and other STDs through sexual health promotion. The AIDS Institute has collaborated with the NYSDOH's STD control program for many years. In a 2010 realignment, the STD control program field staff merged with the AIDS Institute's direct program operations/HIV counseling and testing program to formalize the integration of HIV and STD testing, screening, and partner services and to better serve the clients of both programs.

The realignment brought other STD activities that enhance New York State's ability to interrupt disease transmission into the AIDS Institute as well, including the production of statistical information on reportable STDs and the provision of technical assistance to local health departments for STD surveillance and HIV/STD partner notification activities and field services/case investigation. Health behavior is addressed as it relates to HIV/STDs, partner notification, educational materials development, and outreach programs. The CDC funded Infertility Prevention Project facilitates Chlamydia and gonorrhea screening, and the antibiotic resistance of gonorrhea is being monitored in selected NYS sites. Comprehensive, CDC mandated, HIV/STD

field services training for the eastern quadrant of the United States is provided through a CDC-funded Prevention Training Center.

The 2010 realignment also brought HIV/AIDS surveillance into the AIDS Institute, including extensive surveillance, data management, research, and public health informatics expertise. Using a web-based electronic tracking application developed in-house, the NYSDOH receives and manages over 1.1 million laboratory reports per year electronically from over 80 labs, and thus is the largest and most comprehensive state HIV reporting system in the country. From the beginning of HIV reporting in 2000, NYS has worked towards HIV and STD service integration by using HIV surveillance data to initiate partner service activities. In 2005, the NYSDOH initiated the first comprehensive HIV resistance surveillance system in the U.S. based on reporting of nucleic acid sequences from clinically obtained genotypic resistance tests. HIV/AIDS surveillance activities also include extensive perinatal surveillance, unlinked studies of HIV and hepatitis C in inmates, interviews and chart abstractions of persons in care for HIV/AIDS, and interviews of persons at high risk for HIV/AIDS.

Cost-Saving HIV Special Needs Plans

In response to the shift to Medicaid managed care, the AIDS Institute developed specialized managed care plans, known as HIV Special Needs Plans (SNPs), to address the needs of persons living with HIV/AIDS residing in NYC and their children. 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. Three SNPs are currently licensed and enrolling eligible individuals throughout NYC. As of December 2010, enrollment has grown to more than 10,000. HIV

SNPs have proved successful in engaging and retaining individuals in care, containing and even reducing costs, and achieving better health outcomes for their enrollees. A recent analysis has shown that HIV SNP enrollees have fewer inpatient admissions and shorter lengths of stay, resulting in lower costs per admission. In addition, HIV SNP enrollees show improved access and adherence to appropriate medication regimens. From this analysis, it was estimated that the HIV SNP program reduced Medicaid expenditures by \$4.2 million during the calendar year 2008. This amount is expected to increase with the additional membership the HIV SNPs have realized as a result of the removal of the HIV exemption from Medicaid managed care enrollment, which was implemented in September 2010.

Medicaid Supported Program Infrastructure

All levels of care, from acute to chronic care for persons with HIV/AIDS, are supported by a Medicaid-financed regulatory initiative that requires the provision of elements of the medical home structure, facilitating coordination and continuity of care. The initiative's programs include the hospital-based designated AIDS Centers; the hospital and freestanding diagnostic and treatment center HIV Primary Care Program, under which HIV counseling and testing services and primary HIV medical care are made accessible; AIDS nursing facilities and scatter beds; AIDS home care; AIDS adult day health care; COBRA case management; the Enhanced Fees for Physicians Program; and HIV Special Needs Plans (discussed above). Through focused program

infrastructure development and case management structures, utilization of services and coordination have proven to be more efficient and have benefited HIV-infected persons regardless of their insurance status. These initiatives, built on clinical advancements, have favorably affected health service utilization. Between 1998 and 2008, hospitalizations of HIV-infected persons have declined by more than 6%, with admissions among HIV-infected Medicaid beneficiaries declining by 24%; admissions with a primary diagnosis of HIV or AIDS declined by 46% as admissions of persons with HIV/AIDS for other conditions has increased by 11%; and the average length of stay has declined by 19%.

Opioid Overdose Prevention

Drug overdose is a significant public health issue in NYS. In 2006, life-saving legislation was passed by NYS legislature approving the use of naloxone, an opioid antagonist, to reverse cases of opioid-related accidental overdoses. To date, 66 programs have been approved by NYS Health Commissioner to implement opioid overdose prevention

programs. Of the 353 reversals reported to NYSDOH, emergency services were contacted in at least 55% of the cases, at least 55% needed only one dose of naloxone, 46% of the individuals were under 35 years old, and three (less than one percent) were reported as not surviving.

Evaluation, Research, and Publications

The AIDS Institute conducts and participates in many facets of HIV/AIDS, STD and hepatitis-related research. Coordinated through the Division of Epidemiology, Evaluation and Research, the AIDS Institute routinely evaluates changes in public health laws affecting HIV reporting, HIV testing, expanded syringe access and more. AIDS Institute staff partner with academic institutions, health care providers and federal agencies to conduct research around medication adherence, harm reduction, HIV prevention interventions and service integration as well as epidemiologic studies. Findings are translated into practice recommendations, clinical guidelines, training initiatives, prevention and health care interventions and policy changes.

AIDS Institute staff have authored well over 100 publications documenting research, clinical and policy issues, and program development.

In 1998, the AIDS Institute published a landmark article in the *New England Journal of Medicine*, entitled, *Abbreviated regimens of zidovudine prophylaxis and perinatal transmission of the human immunodeficiency virus* that effected change in the care of HIV-positive women nationally and internationally. This article continues to be referenced in numerous publications, including the federal guidelines on prevention of mother-to-child transmission. More recently, the AIDS Institute authored two articles documenting its successes in reducing MTCT in the *Journal of Public Health Management and Practice*, entitled *Progress in prevention of mother-to-child transmission of HIV in New York State: 1988-2008*, and *Program and policy interventions for prevention of mother-to-child transmission of HIV in New York State*.

To obtain a copy of a list of AIDS Institute staff publications please contact the AIDS Institute's Executive Office.

**AIDS Institute
staff have
authored well
over 100
publications
documenting
research,
clinical and
policy issues,
and program
development**

Oral Health Resource Center

The Regional Resource Center for Oral Health collaborates with the New York/New Jersey AIDS Education and Training Center (AETC) to offer HIV education and training programs for dentists, dental hygienists and dental assistants. The goal of the program is to train dental practitioners to recognize early signs and symptoms of HIV infection and to manage all aspects of patients' oral health needs. The program emphasizes collaboration and health care management through an interdisciplinary

approach inclusive of primary care medical providers along with case managers. To further strengthen this strategy, the AIDS Institute recently convened a national forum on oral health care that brought together oral health experts from across the nation to initiate a standardized approach to oral health care for PLWHA; identify priority areas in policy, guidelines, and education that will promote quality care; and support oral health as part of overall health care for those with HIV/AIDS.

As the AIDS Institute has seen success in reducing the number of new infections, New York State's proportion of cases nationally has declined, resulting in the loss of Ryan White Part B funds

Challenges Ahead

While there are many successes resulting from the HIV/AIDS infrastructure that has been developed in the last 27 years, they must be viewed along with the many challenges that remain. New York State has the heaviest HIV/AIDS disease burden in the nation. Persons of color are disproportionately impacted by HIV/AIDS, and more than one-third of newly diagnosed cases have a concurrent AIDS diagnosis or have an AIDS diagnosis within 12 months. Although improved treatment has resulted in more people living longer, new challenges include increased care and treatment needs, an aging population experiencing multiple co-morbidities, increased diagnoses among younger populations, the role of HIV in diseases other than AIDS, and issues faced by perinatally infected young people as they enter adulthood. New York State's HIV health care delivery system will need to adapt in accordance with health care reform. Twelve new HIV infections are diagnosed each day in NYS, and more than five New Yorkers with HIV/AIDS die every day. The AIDS Institute has evolved and must continue to evolve to meet emerging challenges and adapt to changes in the health care delivery system. Following is a discussion of some of the challenges that lie ahead for the AIDS Institute.

Reductions in Resources: The AIDS Institute's State funding for HIV/AIDS services and activities has been reduced by \$19.4 million since 2008. New York State's federal Ryan White Part B grant, which supports the HIV uninsured care programs and contractors that provide health care and support services, has seen a cumulative loss of more than \$30 million in formula funds since 2006. It should be noted that Ryan White Part B dollars are allocated based on NYS's proportion of living HIV/AIDS cases in the nation. As the AIDS Institute has seen success in reducing the number

of new infections, NYS's proportion of cases nationally has declined, resulting in the loss of Ryan White Part B funds. The CDC Cooperative Agreement, which supports HIV prevention, education and support services, remains 10% lower than it was in 2001. The cuts have led to the elimination of some initiatives as well as substantial reductions in most programs and contracts. These reductions have been made at a time when the demand for HIV-related services is escalating due to infected individuals living longer and new infections continuing to occur.

Sexual Transmission of HIV and other Diseases:

The 2010 realignment within the New York State Department of Health, described above, supports integration of HIV and STDs. In 2011 and beyond, the HIV/STD integration within the Department must be strengthened, and it must be reflected in improved community-based service delivery including testing/screening, partner services, care, prevention education and sexual risk reduction. The AIDS Institute will expand and enhance programs that deal with sexual transmission of HIV and STDs, resulting in increased opportunities for STD screening and treatment. The AIDS Institute must also build on its success with the New York State Condom program, which in 2010 will have distributed over nine million prophylactics, contingent on available funding. While pre-exposure prophylaxis (PrEP) might offer new opportunities for prevention of sexual transmission, questions remain about how PrEP medications should be used outside of a clinical trial in real-life settings, adherence, drug resistance, long-term safety, increased risk-taking behaviors, and, of course, cost.

New Infections Among Young MSM of Color:

Data indicate that new HIV infections among

Challenges Ahead (continued)

young MSM of color have had a significant increase. The number of newly reported HIV infections in young MSM of color (13-24 years of age) in 2003 was 244. In 2008, 428 were reported in the same category. This is an increase of 184 cases (75%) in this category over a five-year period. Young MSM of color, given issues related to youth, poverty, race and cultural underpinnings, are likely to be even further marginalized and isolated. The development of effective prevention interventions and methods of engaging this population is a challenge. In June 2010, a Request for Applications was issued, and eight agencies were awarded funds to provide interventions targeting young gay men/MSM of color in NYS. These interventions are addressing the particular needs and characteristics of young people. A 2011 Request for Applications will include an emphasis on young gay men/MSM addressing HIV/STD prevention, screening and access to care. The AIDS Institute recognizes advances in technology and how young people communicate and get together. Those means of communication are also utilized in public health interventions to reach the groups at higher risk of HIV and STDs.

Aging of the Epidemic: In 2002, 23% of persons living with HIV/AIDS (PLWHA) were 50 years old and older. In 2008, the percentage had grown to more than 36%, or 47,000 people. Seventeen percent of new HIV diagnoses are among people age 50 and over. The AIDS Institute's Division of Epidemiology, Evaluation and Research constructed a population simulation model to project the number of persons living with HIV/AIDS age 50 and over in New York State from 2008 to 2025 and determined that the number of PLWHA age 50 and older will double by 2025. Fifty to sixty percent of PLWHA will be age 50 and

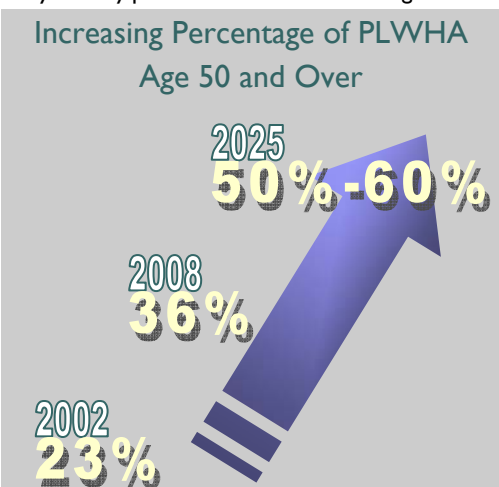
older by 2025. Further, the number of PLWHA age 65 and older will increase by nearly six-fold. These trends underscore the need to integrate culturally sensitive HIV/AIDS health care and supportive services with services for older persons. Program models should incorporate prevention and treatment for co-occurring conditions. Comprehensive systems of care must address multiple medical needs, and prevention programs must not only raise HIV awareness and encourage HIV testing among older people, but also focus on reducing the risk factors for chronic diseases among PLWHA (smoking, physical inactivity, unhealthy diets). HIV as a chronic disease underscores the need for proactive care coordination across clinical settings, case management to address the full range of patients' needs and foster communication among disciplines, and the "enabling" supportive services that help patients access and remain in care. In addition, an analysis of the HIV population's current and future long-term care needs will be required to assure that institutional and community-based long-term care services meet the needs of an aging HIV population.

Residual Mother-to-Child Transmission of HIV:

A review of all transmissions in 2002-2006 demonstrated acute HIV infection (AHI), limited or no prenatal care, substance use, mental health issues, and poor adherence to ARV prophylaxis as factors in residual mother-to-child transmission (MTCT). Strategies to further reduce MTCT are identifying AHI during pregnancy, repeat HIV testing in the third trimester, and increased point-of-care testing in delivery settings with a turnaround time of less than an hour. An expert panel was held in November 2010 to assist in the development of strategies to address New York's residual MTCT as well how New York can incorporate components of the CDC's evolving strategy of eliminating perinatal HIV transmission in the United States. The CDC has indicated that the next competitive continuation of perinatal HIV prevention funds will involve this revised strategy. The long-term goal in this regard includes developing and implementing activities related to the expert panel's recommendations, developing a plan for re-focusing outreach to address the CDC's strategy for eliminating perinatal HIV transmission, and submitting a competitive application for continued CDC perinatal HIV prevention funding.

Hepatitis C: An estimated 304,000 NYS residents have been infected with HCV. Of these, nearly 240,000 people are currently living with

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Challenges Ahead (continued)

In New York State, 26.1 percent of all new HIV diagnoses are concurrent with an AIDS diagnosis, and 33.4 percent of all HIV diagnoses progress to AIDS within one year of diagnosis

chronic infections. Within the HIV population, it is estimated that approximately one-third are co-infected with HCV. Most people have difficulty accessing necessary HCV-related health care services. It is estimated that 50% to 75% of people living with hepatitis do not know their status. Challenges include increasing the number of people who know their HCV status and increasing the number of people treated for HCV across NYS. Work toward meeting this challenge will involve re-launching a statewide media campaign to raise awareness of hepatitis C; making HCV rapid testing kits available in June 2011 to programs demonstrating infrastructure to support HCV rapid testing and linkage to care; implementing the Hepatitis C Assistance Program (HepCAP), which will provide coverage for annual comprehensive medical evaluations, disease and treatment monitoring, HCV testing, mental health treatment and liver biopsies for HCV mono-infected individuals who are uninsured or underinsured; and providing technical assistance to and monitoring the new HCV care and treatment programs.

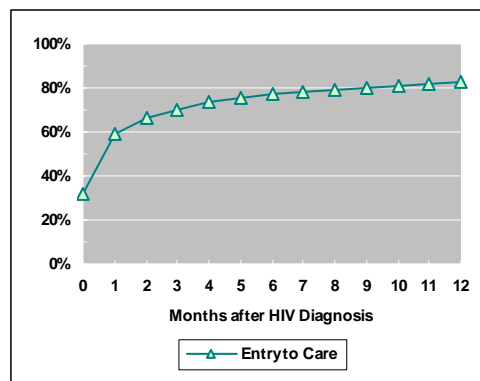
Late/Concurrent Diagnosis and Entry into Care: In NYS, 26.1% of all persons newly diagnosed with HIV have a concurrent AIDS diagnosis. Within one year of HIV diagnosis, 33.4% have AIDS; these persons are considered to have a “late” diagnosis of HIV infection. New York State’s unmet need analysis indicates that as many as 36% of persons in New York who are aware of their status (or more than 45,000 persons) may not have received HIV-related primary care in the past 12 months. A Division of Epidemiology, Evaluation and Research study used viral load data reported through the surveillance system as a marker for assessing whether or not a person newly diagnosed with HIV has entered care for HIV and examined what proportion enter care within 12 months of diagnosis. The study showed that 24% of persons newly diagnosed with HIV did

not have a viral load test within 12 months of diagnosis. In addition, only 85% of persons with concurrent or late diagnosis had a viral load test within one year. These data are particularly disturbing given the comprehensive continuum of HIV care and services in place in NYS. This information demonstrates that it is critical to conduct targeted outreach and make testing, care and services more accessible to individuals who are being diagnosed and entering care very late in the course of their infection.

Workforce Issues: In response to growing concerns about the qualifications of HIV treatment providers in NYS, the AIDS Institute hosted an expert panel, “Defining the HIV Specialist,” in March, 2008. The major challenges highlighted during the meeting were the increasing complexity of managing antiretroviral therapy and the declining number of experienced providers, particularly in upstate and rural areas of NYS. The panel also identified workforce issues facing the quality of care for HIV/AIDS patients in New York related to physician supply, including a dearth of young practitioners choosing to specialize in HIV, decreased financial reimbursement for HIV care, geographic imbalance of HIV specialists, and shifting health care delivery models. In particular, concerns were raised about the quality of care provided by clinicians with low volumes of patients being prescribed antiretroviral therapy. The panel recommended ongoing analysis of the distribution of experienced HIV providers in NYS, monitoring the quality of care provided by low-volume providers, and identifying models of care that can be adapted to meet the needs of PLWHA in upstate New York.

Viability of the HIV Uninsured Care Programs: The continued viability of these priority programs, through which uninsured and underinsured persons with HIV/AIDS receive life-saving medications and care, will depend not only on the continued availability of federal Ryan White funds, but also the continued commitment of State support for the programs through NYS Health Care Reform Act (HCRA). The programs must continue expansion of the APIC program and further increase enrollment through payment of insurance premiums and cost-sharing for eligible individuals to assure access to comprehensive medical coverage.

Transition to Medicaid Managed Care: Until 2010, Medicaid recipients living with HIV/AIDS were exempt from mandatory enrollment in Medicaid managed care and continued to be



Challenges Ahead (continued)

served through fee-for-service Medicaid. In 2010, the exemption was removed for Medicaid recipients living with HIV/AIDS in NYC. The enrollment of persons living with HIV/AIDS in Medicaid managed care plans has begun in NYC and has resulted in a substantial increase in enrollment in HIV SNPs. The AIDS Institute must complete the transition of Medicaid beneficiaries with HIV/AIDS in NYC into managed care plans; improve navigation of providers and consumers in HIV SNPs and mainstream managed care through the provision of technical assistance to AIDS Institute programs and consumers; monitor the quality of care and respond to operational issues and disruptions in care experienced by beneficiaries; and continue long-term planning on the viability of mandatory enrollment in areas outside of NYC where the choice of an HIV SNP is not available.

Retention in Care: The importance of retaining HIV patients in care stands out as a paramount challenge because of the demonstrated linkage of retention to viral load suppression which correlates not only with improved health outcomes and lower health resource utilization, but most importantly with concomitant decreased transmission of virus. Recognizing that treatment is prevention, the health care and prevention communities must unite to focus activities to engage and retain those most likely to fall out of care or use the health care system sporadically. These patients, who often have multiple chronic problems requiring multiple interventions, demand greater resources to link effectively in a sustained relationship with health care providers to achieve multiple health outcomes while reducing the spread of HIV. The goals of the National HIV/AIDS Strategy include increasing viral load suppression rates by 10% among African Americans, Latinos and MSM. In order to achieve this degree of equity among the community, retention in care stands out as the single most important driver to allow successful treatment, which will in turn reduce viral load to undetectable and thereby non-transmissible levels.

Effects of Medicaid Reform on Providers: Many of the HIV-specific rate methodologies that supported specific HIV program initiatives have been subsumed under NYS's Medicaid reform initiatives. The few designated AIDS centers that opted to continue to receive their exempt per

diem payment for inpatient care have been moved to payment through the diagnosis-related group (DRG) system. The enhanced payments for HIV Primary Care Program participants have been eliminated for non-federally qualified health center (FQHC) providers as part of the transition to Ambulatory Patient Groups (APGs), with HIV counseling and testing rates to follow shortly. Payments to AIDS Home Care programs have been capped, and these programs are expected to be subject to the new home care methodology. How payment levels to AIDS nursing homes will be affected by the proposed regional pricing structure for nursing homes generally remains to be seen. It has yet to be determined how these changes will affect the overall reimbursement picture of the site-specific programs developed over the last 27 years in terms of program infrastructure and, consequently, program requirements and quality and utilization of services.

National Health Care Reform: Federal health care reform will have an impact on the structure and delivery of health care and supportive services to persons with HIV, STDs, and hepatitis. The AIDS Institute is analyzing the short- and long-term impact of new models of care and insurance options in the Affordable Care Act. The AIDS Institute must educate HIV service providers and persons living with HIV/AIDS to ensure that the HIV community is aware of the changes that will come with health care reform and continue to monitor the impact of health care reform on health care and supportive services for persons with HIV, STDs, and hepatitis. The impression that categorical funding will not be needed after health care reform initiatives are fully implemented could adversely impact the infrastructure and support services needed to maintain persons in care. The need for HIV supportive services such as case management, transportation, stable housing, and insurance coverage navigators will likely increase due to the many new options for health care coverage. In addition, the AIDS Institute will be involved in discussions with the National Alliance of State and Territorial AIDS Directors (NASTAD) and the President's Advisory Council on HIV/AIDS (PACHA) on health care reform, particularly as it relates to reauthorization of the federal Ryan White legislation. The long term impact of the Affordable Care Act on federal categorical

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**Additional
Publications**

AIDS Institute staff have authored well over 100 publications documenting research, clinical and policy issues, and program development. To obtain a copy of a list of AIDS Institute staff publications please contact the AIDS Institute's Executive Office.



AIDS Institute: Successes and Challenges

Conclusion

The continuum of HIV, STD and hepatitis prevention, care and supportive services needs constant attention. It must continue to 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. 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. The need for basic HIV/AIDS education and other established mainstays of NYS'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.

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The AIDS Institute is a major contributor to the Department of Health's record of public service successes. AIDS Institute programming has shaped the service environment for persons with HIV/AIDS. Twenty-seven years later, maintaining a comprehensive response for New York State will continue to require the full, priority attention of the AIDS Institute and its many partners. New York State is committed to further reducing new cases of HIV and enhancing the quality of care and life of persons living with HIV/AIDS. The AIDS Institute remains a vital component of NYS's infrastructure for a comprehensive response to HIV/AIDS. Further, the AIDS Institute is an organization that has national and even international significance as a model for HIV prevention and care.

History of the AIDS Institute

A chronological history of the AIDS Institute was prepared in conjunction with the 25-year commemoration of the creation of the AIDS Institute. Entitled *The New York State Department of Health AIDS Institute, July 30, 1983 – July 30, 2008: 25 Years of Leadership, Service and Compassion*, the

history documents the AIDS Institute's achievements in policy and program development and includes more detail on the organization's successes. The history is available at http://www.health.state.ny.us/diseases/aids/reports/docs/aids_institute_25-years.pdf