

**2008 Regional Listening Forums:  
Summary and 2009 Progress Report**

**Prepared August 2009**



**AIDS Institute  
New York State Department of Health**

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## **I. Introduction**

A series of regional listening forums was conducted across the State in seven locations by the New York State (NYS) Department of Health AIDS Institute between June and October 2008 (Figure 1). The listening forums were conducted in conjunction with the AIDS Institute's 25-year commemoration and its strategic planning initiative.

Consistent with the AIDS Institute's longstanding commitment to maintain open communication with consumers and providers, the listening forums were designed to provide opportunities for individuals to share questions, concerns and perspectives with the AIDS Institute Director, Humberto Cruz, and senior staff. Within its statewide role, the AIDS Institute has long recognized that there are distinct regional issues and concerns. Conduct of the listening forums on a regional basis not only offered an opportunity for smaller, open discussions but also acknowledged the significant variation across regions (Table 1). Three separate listening forum sessions were held in each region. The individual listening forum sessions were: (1) an early morning session for clinicians; (2) a mid-day forum for consumers; and (3) an afternoon forum for non-clinical health and human services providers. This approach further recognized and accommodated a diversity of perspectives and concerns.

Invitees received letters from Mr. Cruz. In addition to the dates, times and locations of the forums, the letters contained the purpose of the forums as well as a list of ten key priority areas identified by the AIDS Institute for attendees to consider in addressing their comments. The areas encompassed issues pertaining to care, prevention, reimbursement, program coordination, and population-specific needs. Invitees were informed that, while they could consider these topics in framing their comments, they did not have to limit their comments to these areas and were welcome to raise additional issues or concerns. Invitees were encouraged to provide their perspectives, regardless of their ability to attend, and were offered multiple ways to do so, including via a comment sheet that could be completed and returned by fax or e-mail. Many individuals provided written comments prior to or at the listening forums.

More than 500 consumers, clinical and non-clinical providers attended the listening forums (Table 2). Senior staff of the AIDS institute was also in attendance at each of the listening forums to listen, to provide brief updates on current issues, and to respond to specific questions, as appropriate. Forums were conducted with the assistance of a trained facilitator, and comments were transcribed on flip charts. Each began with a welcome, introductions, and brief statement of the purpose of the forums provided by Mr. Cruz.

## **II. Purpose of the Report**

The purpose of this report is twofold. First, it provides a summary of both statewide issues and region-specific concerns identified during the listening forums. Second, the report provides a brief status report and examples of progress on many of the issues that were raised statewide.

The comments heard at the listening forums touched on the successes of the past and pointed out the challenges of the future. This report documents the issues and information presented by clinicians, service providers, and persons living with HIV/AIDS (PLWHA). The report includes a description of overarching issues, statewide themes and recommendations, a report on status and progress associated with statewide issues, and region-specific reports that describe the comments that were received in each region.

In addition to developing this report, the AIDS Institute has assessed the results of the listening forums in relation to its strategic planning process and has incorporated the common themes identified in the listening forums in the strategic plan framework (Appendix 1).

### III. New York State's System of HIV/AIDS Services

Listening forum feedback acknowledged that the New York State HIV/AIDS service delivery system is strong and has been successful in many ways. Below is a brief summary of progress to date.

New York's aggressive, targeted prevention programs have reduced the number of new infections. Its strong, comprehensive health care delivery system has resulted in improved health outcomes and quality of life for those living with HIV/AIDS and reduced overall health care costs.

- In 1993, there were 14,352 newly diagnosed cases. In 2007, the number of newly diagnosed cases was 4,187 – a reduction of almost 71 percent.
- New infections among injection drug users fell between 50 percent and 70 percent in the last 12 years.
- Between 1995 and 2006, HIV/AIDS hospitalizations declined 22 percent, and average length of hospital stay fell more than 27 percent.
- The percentage of women tested prenatally has increased from 67 percent in 1997 to more than 95 percent.
- Perinatal transmission has decreased dramatically, from a high of approximately 500 cases annually in the early 1990s to fewer than ten cases in recent years.
- Deaths among persons with HIV/AIDS declined by 80 percent between 1994 and 2007.

Over the years, the AIDS Institute has consistently and successfully reformed programs to respond to a changing epidemic, emerging needs, and a changing environment. Program models have been modified based on a wide range of inputs, including recommendations from consumers and providers. Resources have been shifted, programs have been modified or eliminated, and new strategies have been adopted to effectively target services to meet the needs of infected and affected populations. As examples:

- **CSPs and MSAs:** From the mid-1980s on, Community Service Programs (CSPs) and, later, Multiple Service Agencies (MSAs) provided a solid foundation for HIV prevention and support services using both a regional and population-based approach. Over the years, the missions of these programs have evolved to include syringe access and other evidence-based interventions that have had a demonstrable impact in preventing new infections and retaining persons with HIV/AIDS in systems of care.
- **DACs:** In 1986, the Department of Health (DOH) implemented the Designated AIDS Center (DAC) program, the first health care system response to the AIDS epidemic. In 1993, DAC program standards were updated to reflect evolving patient needs. In 2008, the standards were again updated to reflect the changing program and organizational features of HIV/AIDS care. Revised standards include new priorities such as improving early diagnosis; increasing focus on engagement and retention in care; promoting wellness, with an increased emphasis on risk factors for chronic diseases including hepatitis C; and expanding the use of health information technology.
- **ADAP:** In 1987, the AIDS Drug Assistance Program (ADAP) was implemented. In 1992, the program was expanded through the implementation of ADAP Plus to meet the needs of a growing uninsured population for ambulatory care and home care services. In 2000, ADAP adopted an insurance continuation component to offer comprehensive coverage for persons with HIV/AIDS in a cost-effective manner. Since inception, the programs have served more than 80,000 PLWHA. The ADAP Plus Insurance Continuation (APIC) program has increased access to comprehensive insurance coverage to over 4,000 people, an increase of over 100 percent. The Uninsured Care Programs have implemented systems to assist individuals with the share of costs (co-payments or cost sharing) associated with using their insurance by coordinating benefits with other coverage at the point of service (pharmacy). This coordination effort saves out-of-pocket expenditures for low income individuals and helps defray up-front costs for ADAP.

- **HIV Primary Care Medicaid Program:** In 1989, the HIV Primary Care Medicaid Program was established to support HIV counseling and testing and coordinated access to HIV care in hundreds of hospitals and diagnostic and treatment centers. In 2003, the program was modified to allow same-day billing of the HIV pre- and post-test visits when the rapid HIV test was utilized. In 2006, Medicaid reimbursement for HIV counseling and testing was extended to hospital emergency departments and part-time clinics.
- **Criminal Justice Initiative:** Since 1991, AIDS Institute-funded community-based organizations (CBOs) have been providing an increasingly comprehensive set of HIV/AIDS-related services within the State prison system. These services supplement anonymous counseling and testing services provided by AIDS Institute staff and services provided by the Department of Correctional Services. The goal is to provide a comprehensive, seamless continuum of quality HIV prevention and supportive services to individuals in correctional settings and ex-offenders returning to their home communities.
- **Syringe Exchange and ESAP:** In 1992, as syringe exchange proved an effective means of HIV prevention, resources were shifted to institute and expand harm reduction programs. 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.
- **HIV/STD Integration:** HIV and sexually transmitted disease (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 DOH field staff and in CBOs has been emphasized to address the continued sexual transmission of HIV and other STDs through sexual health promotion.
- **Treatment Adherence:** In 1998, the treatment adherence initiative was adopted in response to scientific advances in the clinical therapeutics of HIV. The initiative addresses the challenges associated with adherence to complex medication regimens and the importance of the impact of non-adherence to highly active antiretroviral therapy (HAART) on an individual's personal health and that of the community.
- **Streamlined HIV Testing:** In 2003, the model for HIV testing changed from a dedicated counselor model to a streamlined model along with enhanced integration of testing in routine care. In 2005, NYS guidance was issued to streamline HIV counseling in all settings using a simplified written informed consent to help integrate routine testing in medical care settings, promote rapid test technology, ensure entry into care, and better monitor quality of care by improving HIV surveillance to include results of all resistance, viral load, and CD4 tests.
- **Services for Women, Children and Adolescents:** In 2003, funds from multiple sources for services for women, children and adolescents were combined and shifted to maximize resources, with program models modified dramatically to address service needs and changes in the epidemic. The new models included the Family-Centered Care model, which required facilities to cross institutional barriers to provide care to parents and children as family units; low-threshold services for adolescents to ensure relationships that support engagement in HIV health care; and a shift from an integrated model of pediatric care to a center of excellence model. The Families in Transition initiative was re-designed to provide family legal services that address complex legal issues supported by intensive support services.
- **DEBIs:** In 2003, the U.S. Centers for Disease Control and Prevention (CDC) Diffusion of Evidence-Based Interventions (DEBI) programs were widely adopted to ensure prevention programs have strong scientific underpinnings. In 2007, the NYSCondom initiative was initiated to address sexual risk reduction. Within the first six months, NYSCondom was exceeding its goal of distributing 5 million condoms a year.
- **HIV SNPs:** HIV Special Needs Plans (SNPs), fully operational since 2003, are managed care plans that provide an alternative source of care to Medicaid beneficiaries in New York City (NYC) with HIV/AIDS. 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, selected through a competitive process to proceed toward SNP certification, are currently licensed and enrolling eligible individuals throughout NYC. As of July 2009, enrollment is over 5,800.

- **Buprenorphine:** In 2003, statewide regional trainings on buprenorphine were held to promote risk reduction and adherence to care among PLWHA. In 2008, buprenorphine was added to the ADAP formulary. In 2009, a buprenorphine mentorship program was established for physicians outside of NYC.
- **Smoking Cessation:** In 2005, with increases in chronic disease among PLWHA and an assessment showing extremely high prevalence of smoking, a policy decision was made to integrate smoking cessation into HIV care and prevention programs. In 2008, nicotine replacement therapies were added to the ADAP formulary.

The “AIDS Institute Milestones” (Appendix 2) is an overview of the establishment and modification of HIV/AIDS programs over the years. Perhaps more than any other area, HIV/AIDS programs have had to be flexible and quickly adapt for services to be relevant and effective, and they must continue to evolve. The AIDS Institute engages in strategic planning to help make sure that programs and services are as effective as possible in meeting identified needs. The listening forums are an essential component of this process.

The successes resulting from the HIV/AIDS infrastructure that has been developed in the last 25 years must be considered along with the many challenges that remain. New York 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, and increased diagnoses among younger populations. There are approximately 16 new HIV infections in NYS every day, and more than five New Yorkers with HIV/AIDS die every day.

## IV. Overarching Issues

In compiling this report, the AIDS Institute identified the fact that some important, overarching issues that were raised are larger issues, not specific to HIV/AIDS. Forum participants noted that these issues directly affect PLWHA as well as both clinical and non-clinical providers, and that they influence the extent to which needs are met. The overarching issues reflect that HIV/AIDS exists within a larger state and national context and that there are many entrenched societal issues. Examples included:

- **Access:** Lack of universal access to primary and preventive care and supportive services.
- **Budget Reductions and Health Care Reform:** Uncertainty about the impact of the fiscal crisis and health care reform initiatives on providers and consumers.
- **Changing Demographics:** Increasing diversity and aging of NYS’s population; aging of individuals with HIV/AIDS and co-morbidities.
- **Continuity of Care from the Criminal Justice System to the Community:** Family separation and barriers confronted by individuals returning to the community from the criminal justice system.
- **Health Disparities:** Communities of color are disproportionately affected by HIV/AIDS and other health issues.
- **Health Literacy:** Need for improved “health literacy” and “health systems literacy” for all populations.
- **Housing:** Housing status influences HIV risk, access to and retention in care, and health outcomes. Homelessness or unstable housing leads to greater HIV risk for uninfected persons and, for HIV-infected persons, it presents barriers to starting and staying in care.
- **Intersection of HIV/AIDS, Substance Use and Mental Health:** Need for improved access and greater integration of care and services across sectors.

- **Poverty:** Poverty, unemployment and lower socioeconomic status are significant factors which may lead to HIV risk and prevent people from accessing prevention interventions, testing, care, and supportive services.
- **Resource Needs:** Insufficient resources to support the full complement of HIV/AIDS services in every community statewide.
- **Stigma:** Multiple stigmas and discrimination related to issues including but not limited to race/ethnicity, HIV/AIDS, sexual orientation, substance use, poverty, and criminal justice involvement.

In its ongoing statewide role, the AIDS Institute continues efforts to address or influence these larger issues. It does so by bringing specific concerns that are not within its purview to the attention of relevant parties and by collaborating with others to address problems that the AIDS Institute and its community partners cannot solve by themselves.

## V. Statewide Issues

### A. Themes and Recommendations

In each region, participants stated that they appreciated the opportunity to participate in the listening forums. Participants spoke eloquently about the importance of the continuum of HIV/AIDS programs and services that has been developed over the past 25 years. They also expressed their appreciation to the AIDS Institute. Participants also spoke eloquently about service needs. Each listening forum offered a wide range of comments and recommendations.

#### *Prevention*

- **Education and Outreach:** Enhanced education and outreach was called for, and participants noted that prevention education needs to begin early – in high school – and that State Education Department mandates must be enforced. Enhanced social marketing, public service announcements, and outreach targeted to marginalized populations were cited as needs.
- **HIV Testing and Integration with STD Services:** Expanded and integrated testing was called for by providers, consumers, and clinicians. Participants noted that HIV testing should be maximized by integrating it with other public health prevention activities, including STD testing. Barriers to testing were noted, including limited funding for test kits, limited shelf life of test kits, and competing priorities in emergency departments.
- **Harm Reduction:** Harm reduction continues to be a critical need. Participants noted the need for additional syringe exchange programs and increased availability of buprenorphine.

#### *Health Care*

- **HIV Specialists:** There is a lack of HIV specialists. Incentives are needed to attract clinicians to HIV care and to encourage HIV specialists to practice in underserved regions of the State.
- **ADAP:** There was praise of ADAP, but concerns were expressed about ADAP's coverage of HIV-related care and treatment only and outpatient care only, particularly as persons develop multiple non-HIV-related co-morbidities. The ADAP Plus Insurance Continuation (APIC) program's required payment of the first insurance premium is a barrier for some individuals.
- **Hepatitis C:** Hepatitis C is an emerging epidemic which warrants a comprehensive response. Integrated testing, better data for monitoring the epidemic and planning services, coordinated treatment for HIV and hepatitis C, and treatment for the mono-infected are needed.

- **Dental Services:** Access to dental services is critical for PLWHA, but there is a shortage of dental services.
- **Mental Health:** Mental health services are needed for PLWHA to assure access to care and adherence to treatments, but access is limited. There is a shortage of mental health practitioners, particularly psychiatrists able to prescribe medications. Substance use and mental health issues complicate HIV treatment and adherence and can undermine prevention. There is a large number of substance users who need psychiatric care and medications.
- **Long Term Care:** Persons living with HIV/AIDS sometimes remain in hospitals receiving an unnecessary level of care while awaiting long term care beds.
- **Treatment Adherence:** Treatment adherence support is essential, and specialized treatment adherence is needed for substance users and persons with mental illness.
- **HIV/AIDS as a Chronic Disease:** With recognition of HIV/AIDS as a chronic disease, movement to a chronic disease model must proceed. Interaction and collaboration with other systems of care for other diseases are critical. Some participants expressed concern about labeling HIV as a chronic disease and ignoring related stigma and discrimination.
- **Role of the Consumer:** Consumers need to be well informed, and they need support to actively participate in their disease management.

### *Health Care Financing and Health Coverage*

- **Medicaid Reimbursement Reform:** The multi-year Medicaid restructuring that is underway will reallocate funds from inpatient to outpatient/ambulatory care settings and create a medical home model for Medicaid beneficiaries. Ambulatory Patient Groups (APGs) will serve as the basis for medical service payments in ambulatory care settings. HIV enhanced rates at Designated AIDS Centers (DACs) and HIV Primary Care Programs will transition to APGs in conjunction with this restructuring.

The AIDS Institute and the Office of Health Insurance Programs are working together to preserve reimbursement for critical HIV-related services within the APG-based payment system. APG-based reimbursement commenced in December 2008 for hospital outpatient departments and is pending federal approval for use in freestanding community health clinics, with a retroactive effective date to March 2009. APG payments are based upon the proper coding for the intensity of services provided, similar to Medicare reimbursement.

Listening forum participants emphasized the importance of preserving and enhancing reimbursement for HIV-related services within the State's Medicaid restructuring efforts. Concerns were raised that rate setting reform will fail to adequately reflect the complexity and resource intensity of services provided to HIV-infected Medicaid patients. Special attention was given, by both clinicians and consumers, to the critical role of DACs as an HIV medical home which requires dedicated reimbursement for infrastructure and quality assurance activities required to meet AIDS Institute program standards.

- **Medicaid Managed Care for Persons with HIV and AIDS:** Federal approval is currently pending for mandatory managed care enrollment of Medicaid beneficiaries with HIV and AIDS. Upon approval, the State will commence enrollment in NYC. Mandatory enrollment will require eligible beneficiaries to choose enrollment in a mainstream managed care plan or an HIV SNP. HIV SNPs are Medicaid managed care plans for HIV-positive Medicaid beneficiaries residing in NYC and their children. HIV SNPs provide access to high quality health care and essential supportive services in the community.

NYC forum participants requested a slow phase-in to permit time to educate consumers about their choices in a mandatory environment. Consumers expressed concerns that managed care enrollment will adversely impact Medicaid beneficiaries' access to services and disrupt ongoing provider relationships.

For regions outside of NYC, long term planning was requested on the viability of mandatory enrollment in areas where the choice of an HIV SNP is not available.

- **Restriction on Dual Enrollment in COBRA Case Management and HIV/AIDS Day Care Programs:** Consumers expressed concerns over the Medicaid restriction of dual enrollment in both COBRA case management and HIV/AIDS Day Health Care programs (ADHC).

### *Supportive Services*

- **Transportation:** Transportation services are needed in every community and region of the State, whether they are urban, suburban or rural. The lack of transportation is a significant barrier to care, and transportation needs encompass both clinical and supportive services. Medicaid-funded transportation is limited or unavailable, and Medicaid restrictions are a significant barrier.
- **Case Management:** Culturally and linguistically appropriate case management services are essential to ensure access to and retention in care, especially for populations with special needs (e.g., mental health, substance use services). COBRA case management should continue to be supported and turnover minimized through adequate reimbursement and relaxed staffing standards.
- **Food and Nutrition:** Good nutrition is essential to improve medical outcomes. Access to food and nutrition services is critical. Barriers to be addressed include documentation requirements and the requirement to transition to independence within a defined time period.
- **Substance Use-Related Services:** There is a need for greater access to the full range of addiction and recovery programs and harm reduction services.
- **Legal Services:** Legal services and advocacy are essential for some individuals to be able to engage in care and access adequate housing. Dedicated HIV legal services must be available for all PLWHA, including those with and without children.
- **Translation and Interpretation:** Access to and retention in care requires translation and interpretation services for those who speak a foreign language and for those living with a disability (e.g., deaf, hearing impaired, or visually impaired).
- **Housing:** Access to adequate housing has a direct impact on health and well-being, yet the housing needs of many PLWHA are unmet.

### *Population-Specific Issues*

The AIDS Institute was strongly encouraged to maintain both a broad population approach as well as tailored programs and services for defined populations. The following populations and concerns were noted:

- **Adolescents and Young Adults:** Young persons have specific HIV prevention and care needs. Specific concerns noted were the importance of a “safe space” for adolescents, adherence and disclosure issues, distinct needs and programs for perinatally infected youth and for youth who are behaviorally infected, and the unique and complex needs of parenting teens.
- **Communities of Color:** Communities of color, particularly African Americans and Latinos, continue to bear a disproportionate burden of HIV/AIDS. African American women are especially vulnerable and require targeted care, treatment, and prevention interventions that recognize other social issues (e.g., stigma, discrimination, mistrust of the health care system, domestic violence). At the same time, the distinct needs of Asians and Pacific Islanders and of Native Americans cannot be overlooked.
- **Immigrants, Migrants and Seasonal Farm Workers:** Fear of deportation can prevent many immigrants from accessing care and services. Immigrants and migrants, as well as many seasonal farm workers, also face cultural and language barriers, and many have low health literacy.
- **Individuals Involved in the Criminal Justice System:** The criminal justice system, including prisons and jails, continues to be a critical setting for HIV/AIDS prevention and treatment programs. Additional

concerns pertain to coordination and continuity of care upon release to the community and the importance of timely enrollment in or reinstatement of Medicaid and other public benefits.

- **Individuals with HIV/AIDS and Co-Occurring Conditions:** HIV/AIDS often overlaps with other illnesses. These include drug addiction and mental health disorders, as well as STDs, tuberculosis (TB) and hepatitis. Persons living with HIV/AIDS who are multiply diagnosed, particularly persons with psychiatric disorders (e.g., severe mental illness, depression, trauma) and/or physical disorders, face particular challenges in adhering to their HIV/AIDS treatment regimens. Specialized treatment adherence programs are often required to assure treatment adherence.
- **Mature Adults:** Adults age 50 and over are confronted with distinct challenges not faced by younger persons. Despite misperceptions that mature adults do not have prevention needs, targeted outreach, education, prevention messages, and materials are necessary. For mature adults living with HIV/AIDS, “prevention fatigue,” “treatment fatigue,” co-occurrence of HIV/AIDS and other chronic conditions as well as specific case management needs are of concern. For both HIV-positive and HIV-negative older persons, resuming dating can be accompanied by the risk of transmitting or acquiring HIV/AIDS.
- **Men Who Have Sex with Men (MSM):** This population may be underrepresented in epidemiologic data upon which needs assessments and resource allocation decisions are based. Targeted services are needed, including a sustained, targeted social marketing campaign. There is an increased need for focused formative research targeting young MSM and MSM of color.

### ***Other Concerns***

- The need for strengthened linkages between health care providers and CBOs, as well as coordination between State and local agencies, was noted.
- Effective and well-staffed consumer advisory boards are required in order for programs and services to best meet the needs of persons served.
- Streamlined and standardized contractual requirements should be explored.
- User-friendly data systems that are responsive to individual agency needs are necessary for individual program planning and evaluation purposes, yet some participants noted that the AIDS Institute Reporting System (AIRS) is not easily manipulated.
- Stigma and discrimination continue to negatively affect both consumers and service providers.

### ***B. Status and Progress***

Following are brief status reports and examples of progress in the areas where issues were raised statewide.

#### ***Prevention***

##### **Education and Outreach**

- A condom access program has been established that provides over 5 million free condoms each year to CBOs, health care facilities, and local governments.
- Three separate social marketing campaigns are in various stages of development and implementation, including the continuation of HIV Stops with Us in NYC and Buffalo, anti-stigma and sexual health campaigns for African American men who have sex with men in Buffalo, Rochester and on Long Island, as well as a campaign to address the stigma associated with HIV/AIDS.
- Legislation is pending that would create a grant-funded initiative to support the delivery of comprehensive sex education in schools. In addition, the AIDS Institute promotes the delivery of HIV prevention education in schools.
- The AIDS Institute-sponsored Western and Finger Lakes Region HIV/STD/Viral Hepatitis Public Health Coalitions -- made up of local and county health departments in the Western and Finger Lakes regions of

NYS -- held a meeting in June 2008 on "Creating Partnerships Between Schools and Public Health to Promote Comprehensive Sex Education for Young People." The meeting included a presentation on current data on HIV, STDs, and pregnancy among adolescents. As a result, a work group has been formed to promote sharing of resources and strategies for effective partnering with schools.

- In early 2008, the AIDS Institute rolled out the training, "Developing Skills for Enhanced Outreach," across NYS by building the capacity of ten Regional Training Centers to deliver this training statewide. The training is designed to provide outreach workers with skills to increase their effectiveness in conducting outreach to hard-to-reach populations using an Enhanced Outreach Model. To date, 311 outreach workers and other human service workers have been trained.

### **HIV Testing and Integration with STD Services**

- Three HIV testing bills are pending in the State legislature. One bill authorizes HIV testing to be part of a signed general consent to medical care that is durable and remains in effect until it is revoked or expires. The legislation also calls for tailored HIV counseling messages based on whether the test indicates infection; referral to medical care for those who test positive; HIV testing in situations involving occupational exposure where the source person is deceased, comatose, or unable to provide consent; and the offer of an HIV test to every individual between the ages of 18 and 64 in hospital inpatient, outpatient, and emergency departments and in diagnostic and treatment centers. The legislation also removes the requirement that a physician certify that informed consent has been obtained before ordering HIV-related testing by a laboratory or other facility. The other two bills eliminate separate written consent and call for the offer of an HIV test to every individual between the ages of 13 and 64 in emergency rooms and certain other settings.
- Routine HIV/STD testing in medical care settings has been and will continue to be incorporated into program models.
- Integration among DOH field staff and in CBOs has been emphasized to address the continued sexual transmission of HIV and other STDs through overall sexual health promotion.
- The AIDS Institute continues to provide HIV rapid test kits, incentives, and technical assistance to agencies expanding access to HIV testing services.
- A revised guidance for local health departments has expanded options for reimbursement of HIV counseling and testing services at county health department STD clinics.
- The AIDS Institute has convened a Department-wide sexual risk reduction work group.
- The AIDS Institute is collaborating with the NYC Department of Health and Mental Hygiene on a syphilis advisory group.
- The brochure, "Diseases that Can Be Spread During Sex," has been redesigned, updated and is now available in English and in Spanish on-line (<http://www.nyhealth.gov/publications/3805.pdf>) and through the Distribution Center. This popular material presents a wealth of information about STDs, HIV/AIDS and hepatitis, discusses prevention strategies and provides referral resources for both STD and HIV testing.
- Eleven offerings of the AIDS Institute's recently developed two-day training, titled, "Sex, Gender, and HIV/STDs," are available. This training helps health and human services providers promote sexual health among their clients by building their capacity to talk sensitively and non-judgmentally about sexual identity, gender identity and sexual behaviors. Topics covered during the training include: sexual and gender identity; strategies for talking with clients about sexual health issues; HIV/STD prevention and harm reduction strategies for sexual behaviors.
- The AIDS Institute and the NYS Bureau of STD Control have formed a work group to facilitate the implementation of efforts to integrate HIV and STD partner services.

### **Harm Reduction**

- In 2009, two new syringe exchange programs (SEPs) will be approved – one in Albany and one in Staten Island – and the AIDS Institute is exploring expansion into two additional regions of the State. In addition, peer-delivered syringe exchange was approved as a new model of exchange after documented

success as a pilot program. In peer-delivered syringe exchange, active SEP participants are identified, recruited and trained, and once peers demonstrate that they are able to conduct syringe exchange appropriately, they are issued the necessary equipment and documents to offer SEP services in their social networks. Peers provide sterile syringes, education, and referrals to the most disenfranchised at-risk users – populations that would otherwise not have them. Twelve of the 17 authorized SEPs have been approved for the peer model. For two programs in upstate New York, peer-delivered syringe exchange has expanded syringe access into surrounding counties and rural areas that do not have SEPs.

- New, dedicated State funding was made available in 2009 to support the purchase of syringes.
- The Commissioner of Health wrote a letter to President Obama urging the administration to support lifting the ban that precludes federal funds from being used for syringe exchange programs, citing the success of syringe exchange programs in NYS and the need for this effective intervention in the fight against HIV. Legislative language lifting the federal ban is under consideration.
- The AIDS Institute continues to explore options through ESAP to expand access to sterile syringes (especially in areas where there is no syringe exchange available) through pharmacy sales, provision by medical providers at fixed site and mobile approaches, and through outreach voucher programs. The AIDS Institute has sought to increase the number of pharmacies participating in ESAP, including sending letters to thousands of pharmacies encouraging them to register. In the last month, 32 new pharmacies applied, and one applied to become a collection site. In addition, some providers have hired peer workers who speak a variety of languages to reach out to pharmacies owned by people from other countries (e.g., Russia, China), and some providers, in partnership with pharmacies, have implemented ESAP voucher programs, providing vouchers to clients who can redeem them at partnering pharmacies.
- Buprenorphine, an alternative substance abuse treatment, was added to the ADAP formulary in 2008 and is covered by Medicaid.
- Between 2005 and 2007, the number of buprenorphine prescriptions per year increased more than threefold, and the number of physicians prescribing buprenorphine increased fourfold.
- A buprenorphine mentorship program was recently established to increase the number of clinicians prescribing buprenorphine in upstate New York.
- A new "Addressing Sexual Risk with Drug Users and their Partners" one-day training has been developed to build participant knowledge and skills in offering sexual harm reduction options to substance users. Expanded access to syringes, other harm reduction services and drug treatment options have helped people greatly reduce their substance use-related risks for HIV. The latest research shows that sexual risk behaviors play a significant role in new cases of HIV among people who use drugs and alcohol. Eight offerings are scheduled between July and December 2009.

## ***Health Care***

### **HIV Specialists**

- The AIDS Institute no longer offers guidelines for defining "HIV Specialists," but defers to professional societies that have developed formal processes for the recognition of expertise in HIV care, including the American Academy of HIV Medicine (AAHIVM) and the HIV Medical Association (HIVMA). The criteria set forth by these organizations resemble board certification criteria, including formal tests and the fulfillment of continuing medical education (CME) requirements. The NYS DOH AIDS Institute aims to ensure that the statewide system of HIV care be as effective, as high quality, and as universally available as possible, ensuring that HIV specialist care continues to exist and thrive in response to changes in the epidemic and advances in standards of care. One of the AIDS Institute programs that helps meet this goal is the Nicholas A. Rango HIV Clinical Scholars Program. The purpose of the program is to train highly qualified clinicians who are uniquely motivated to provide care to people with HIV/AIDS. This program is currently being modified to address workforce shortage concerns.
- In an effort to attract additional health care providers and widen the level and amount of HIV educational materials and messages, the AIDS Institute's Clinical Education Initiative (CEI) will employ new media outlets, such as LinkedIn, Facebook, and online CME web-based trainings. One such project – Widget –

streams web-based educational podcasts on non-occupational post-exposure prophylaxis (nPEP), occupational post-exposure prophylaxis (oPEP), pediatric PEP, and acute HIV infection. The Widget is geared to be placed on computers throughout NYS, especially in emergency rooms. Through these projects, the CEI hopes to increase CEI visibility, reach low- and high-volume providers in rural and urban settings, connect providers to existing websites and educational tools, and assess provider educational needs on a larger scale.

### **HIV Care**

- The AIDS Institute is considering updating its clinical guidelines to broaden the indications for initiating anti-retroviral (ARV) therapy to include asymptomatic patients whose CD4 count is approaching 350, rather than waiting until it decreases to below 350, and patients who are initiating hepatitis B treatment. In addition, clinicians might be urged to carefully evaluate patients for certain co-morbidities or co-existing conditions that may influence the decision of when to initiate ARV therapy. Clinicians would also be encouraged to involve each patient in the decision to initiate ARV therapy due to the belief that any patient, regardless of CD4 count, should begin treatment if they understand the treatment commitment and wish to receive it.

### **Hepatitis C**

- A request for applications (RFA) for new funding to support comprehensive hepatitis C services for both mono-infected and co-infected persons was recently issued. It is anticipated that new programs will be effective on or about July 1, 2010.
- The AIDS Institute has begun development of a Hepatitis C Assistance Program, modeled on and administered by ADAP, to provide access to hepatitis C treatment services through enrolled providers. The program targets hepatitis C (HCV) mono-infected individuals who are uninsured or underinsured and meet certain criteria (i.e., financial, residency, medical). Coverage will include annual comprehensive medical evaluations, disease and treatment monitoring, HCV testing (i.e., PCR, genotype), mental health treatment and liver biopsies.
- The AIDS Institute is advancing public awareness through National Viral Hepatitis Awareness Month and World Hepatitis Day events. It also launched a statewide public awareness campaign to urge New Yorkers to learn about hepatitis C.
- The AIDS Institute is playing a significant role in the development of a new NYS Viral Hepatitis Strategic Plan. The plan will include a hepatitis C framework with specific objectives pertaining to prevention, education, surveillance and research, medical care and treatment, policy and planning. It is anticipated that the plan will be completed by the end of 2009.
- In March 2009, the AIDS Institute hosted the seventh statewide hepatitis C conference, “Hepatitis C – Rising to the Challenge,” that covered topics such as the future burden and costs associated with chronic hepatitis C, a hepatitis C treatment update, hepatitis C and communities of color, hepatitis C treatment challenges, and hepatitis C prevention, including the latest information on acute hepatitis C in HIV-infected MSM.
- The AIDS Institute functions as the National Viral Hepatitis Technical Assistance Center, which supports the 55 state and large city Adult Viral Hepatitis Prevention Coordinators. As part of its work, the Technical Assistance Center has completed a 60- page guide on strategic planning to assist coordinators with the development of their own statewide plans to address viral hepatitis, presented at two national conferences on successful hepatitis trainings, and participated in the U.S. Health Resources and Services Administration (HRSA) Minority Health and Health Disparities initiative to build capacity to overcome health disparities in the treatment of hepatitis C in community health centers.

### **Dental Services**

- The ADAP Plus cap on dental visits was lifted to 12 per year, with flexibility to override the visit limit with documentation from the clinician. As a result, program expenditures for dental services have increased by almost 25 percent.

- A dental consultant has joined the AIDS Institute's Office of the Medical Director to focus on access to and quality of oral health services.
- A survey was conducted to identify barriers to oral health care from the consumer perspective. Responses have been received and data analysis is underway.
- The AIDS Institute has reached out to dental schools to arrange for presentations to dental students and faculty regarding access and barriers to oral health care for PLWHA.
- The AIDS Institute is reviewing the oral health care guidelines to determine if an update is needed.
- The AIDS Institute, through the New York/New Jersey AIDS Education and Training Center (AETC), coordinates the Oral Health Regional Resource Center. Continuing education programs, including individualized preceptorships, are offered throughout the state to oral health clinicians in an effort to enhance the quality of services provided to HIV-infected patients. In addition, through the Oral Health Regional Resource Center, the AIDS Institute provides technical assistance to oral health clinicians to implement HIV testing chairside in dental clinics and private practice offices. These activities improve the prospect of identifying the disease earlier. Further, through the Oral Health Regional Resource Center, the AIDS Institute also provides HIV-specific faculty development courses for dental hygiene schools.

### **Mental Health**

- The ADAP Plus cap on mental health visits was lifted to 30 per year, and there is flexibility to override the visit limit with documentation from the clinician. As a result, program expenditures for mental health services have increased by 14 percent.
- A recent re-solicitation of Ryan White Part B funds supporting mental health services was completed to assure that persons with HIV/AIDS have access to a range of services that facilitate retention in mental health and primary care and that increase medical and psychiatric treatment adherence. In addition, funding was made available for the provision of training and technical assistance to improve the medical outcomes of PLWHA. This funding increases the number of health care providers who are educated and motivated to counsel, diagnose, treat and medically manage individuals with mental illness and HIV infection through the delivery of an array of consultation and training interventions throughout the state. As a result, 20 programs throughout the state received funding to provide a continuum of mental health services to persons with HIV/AIDS. Three programs received funding to provide training and technical assistance statewide.
- The importance of mental health services to address the underlying issues that cause people to engage in risky behaviors is recognized as a crucial component of a comprehensive HIV prevention program. This is reflected in pending requests for applications for HIV/STD prevention services for women and gay men/men who have sex with men.
- In an effort to attract additional health care providers and enhance the level and amount of HIV educational materials and messages available to health care providers, the AIDS Institute's Clinical Education Initiative has created a Center of Excellence in mental health. Clinicians across the state are being trained to enhance mental health care for patients or teach other clinicians through a train-the-trainer course.

### **Long Term Care**

- The State's multi-year health care restructuring includes an extensive redesign of long term care service delivery and payment structures. The AIDS Institute is working within the Department and with providers to identify the unique long term care needs of the HIV/AIDS population which is often a younger, more mobile population with numerous chronic co-morbidities when compared to a frail geriatric population.
- The AIDS Institute will coordinate an evaluation of the current AIDS nursing home and home care programs and identify the emerging long term care needs of the HIV/AIDS population. The AIDS Institute will provide expertise in Medicaid rate restructuring to reflect the complexity and resource intensity of services provided to HIV-infected Medicaid patients.

## **Treatment Adherence**

- With the recent treatment adherence solicitation, the model was modified based on knowledge drawn from health services research and evidence-based literature that consistently demonstrate better health outcomes for people living with HIV who receive adherence support services that are closely integrated with medical care services.
- Emphasis on treatment adherence has been and will continue to be incorporated into a variety of initiatives and program models.
- The AIDS Institute has convened a workgroup to assist in the development of a new training, “Promoting Primary Care and Treatment Adherence for HIV-Positive Individuals.” This training will be rolled out statewide in December 2009 and is designed to increase awareness of non-physician health and human services providers about HIV primary care guidelines and treatment adherence.
- The Office of the Medical Director facilitates a Treatment Adherence Quality Learning Network in collaboration with the NYC Department of Health and Mental Hygiene. The aim of the network is to better coordinate models of service provision, facilitate peer-to-peer learning and ensure statewide quality of care for treatment adherence services.

## **HIV/AIDS as a Chronic Disease**

- Program models within health care initiatives are being reviewed and modified to incorporate prevention and treatment of co-occurring conditions, such as cardiovascular disease and diabetes, and models that are responsive to the needs of an aging population.
- AIDS Institute staff are actively engaged in analysis of Medicaid data to examine the extent and impact of co-occurring conditions among Medicaid beneficiaries with HIV/AIDS. This analysis will inform program and policy development.

## **Role of the Consumer**

- The Leadership Training Institute (LTI) was modified to incorporate a three-day patient self-management training, including a peer mentor model, to assist PLWHA in accessing and staying in care and improving health outcomes. In addition, the AIDS Institute is expanding the LTI to add a component involving outreach to PLWHA to expand their meaningful participation in Ryan White HIV Care Networks and other HIV/AIDS planning bodies.
- Consumer involvement continues to be emphasized in planning statewide programs via Ryan White HIV Care Networks, the HIV Prevention Planning Group, and consumer advisory committees.
- A hepatitis C community work group is helping to inform programs and policies related to hepatitis C.
- The AIDS Institute continues to use input from focus groups and discussion groups convened as new initiatives are planned or existing initiatives are modified.
- The AIDS Institute’s Quality of Care Program actively engages consumers in quality improvement efforts through the statewide Consumer Advisory Committee (CAC). The committee meets quarterly and members participate on the AIDS Institute’s Quality of Care Committee. The CAC routinely reviews AIDS Institute-developed materials designed for consumers.

## ***Health Care Financing and Health Coverage***

### **Medicaid Reimbursement Reform**

- The AIDS Institute has commenced an ongoing process of educating providers and consumers about the transition to Ambulatory Patient Groups (APGs) for care in outpatient and community clinic settings.
- The AIDS Institute supports the continued integrity of the DAC program and has carved the therapeutic visit out of the APGs. Work will continue to fine-tune various aspects of the APG methodology to assure it adequately reflects the evolving needs of HIV-infected Medicaid patients. In addition, the AIDS Institute has urged HIV providers in NYC to ensure they have contractual relationships with SNPs and

managed care plans in preparation for the removal of the HIV exemption from mandatory Medicaid managed care.

- The AIDS Institute has informed DACs of the opportunity to lead the Department of Health's patient-centered medical home program within their institutions, as DACs have served as a medical home for people with HIV for more than 20 years. In addition, DACs are encouraged to explore the option of expanding the scope of AIDS Centers to treat non-HIV patients with chronic diseases.
- The impact of emerging Medicaid rate reform initiatives on the fiscal health of affected HIV service providers and HIV-infected Medicaid beneficiaries' access to critical services will be evaluated.

### **Medicaid Managed Care for Persons with HIV/AIDS**

- The federal Center for Medicaid and Medicare Services (CMS) has reviewed the State's proposal to remove the HIV exemption for Medicaid-eligible individuals and has requested additional information, which the AIDS Institute has provided.
- Over the past year, the AIDS Institute has collaborated with federal, State, and NYC agencies to prepare a roll-out plan for removing the HIV exemption for Medicaid-eligible individuals, starting with NYC. The AIDS Institute is working with the HIV service provider and consumer communities to facilitate enrollment and minimize the need for auto-assignment during mandatory enrollment. Ongoing meetings with service providers, clients and advocates are underway to assure that individual questions and concerns are adequately addressed. In 2008 and 2009, trainings on Medicaid managed care for persons with HIV and AIDS were conducted for 79 case management providers reaching 1,200 participants. In addition, the NYS DOH posted a frequently asked questions document on Medicaid managed care for people with HIV and AIDS on the Department website.
- The AIDS Institute is working closely with the NYS DOH Division of Managed Care; the NYC Department of Health and Mental Hygiene, Bureau of Health Insurance Programs; the NYC Human Resources Administration (HRA); the NYC HIV AIDS Services Administration (HASA); and other organizations to ensure quality measures are in place for HIV care and to improve features of the enrollment process.
- Long term planning will continue on the viability of mandatory enrollment in areas outside of NYC where the choice of an HIV SNP is not available. An assessment of the NYC enrollment experience as well as HIV network capacity in other regions of the State will be undertaken.

### **ADAP**

- The current regulations governing the ADAP program are being revised from a fixed income cap to income eligibility that is tied to the federal poverty level at 435 percent of federal poverty level. In addition, the program proposes to determine financial eligibility based on net income adjusted for Medicare and Social Security withholding and the cost of health care coverage paid by the applicant. Further, federally recognized retirement plans will be excluded as a counted asset for program eligibility purposes.
- The AIDS Institute is increasing access to comprehensive health insurance coverage through the ADAP Plus Insurance Continuation (APIC) Program, which will enhance access to comprehensive care, including care that is not related to HIV.
- ADAP staff have conducted regional presentations in response to questions raised in the listening forums on ADAP 101, Medicaid spenddown, and coordination of benefits.
- The AIDS Institute is exploring the development of software that would allow case managers to input financial, demographic and clinical information to help guide determination of eligibility for various health care coverage options available to them.

### **Restriction on Dual Enrollment in COBRA Case Management and HIV/AIDS Day Health Care (ADHC) Programs**

- HIV/AIDS Adult Day Health Care (ADHC) services include a case management model where the ADHC serves as the primary case management source. There may be instances in which the client benefits from

the mental health and/or substance use services provided by the ADHC but also has individual or family/collateral needs that can only be addressed by a community based provider, such as COBRA. Enrollment guidelines include provisions for dual enrollment in both programs on a time-limited basis under specific conditions.

## ***Supportive Services***

### **Case Management, Transportation, Translation and Interpretation**

- The AIDS Institute plans to enhance the availability of support services for PLWHA that facilitate access to care and improved health outcomes via a recent solicitation. Services will include case management, psychosocial support, health education and risk reduction, treatment education, and linguistic services. Notably, resources for and availability of transportation services will be substantially increased to address needs and gaps identified throughout the State and to remove a significant barrier to access to services.
- The AIDS Institute has attempted to obtain increases in reimbursement rates for COBRA case management programs but has been unsuccessful due to the State's fiscal crisis. The AIDS Institute is working to restructure the COBRA reimbursement methodology to better support services.
- In recognition of the lack of uniformity in language interpretation services in health care settings, the AIDS Institute and the Office of Minority Health initiated a joint project called, "Promoting Cultural and Linguistically Appropriate Services (CLAS)." This project brought together an expert advisory panel and included research to define core competencies and training standards for this critical service. The research included a comprehensive literature review and extensive interviews with language interpreters and language interpreter training programs and a focus group with health care administrators. The report will include recommendations to the NYS DOH and health care providers and will be available in early 2010.

### **Food and Nutrition**

- The AIDS Institute's nutrition initiative was modified to incorporate work toward food security and independence of clients in response to issues raised by consumers and providers in a statewide nutrition needs assessment. While the goal is to graduate participants within 18 months, there is flexibility with regard to that time period based on consumer needs and readiness. The intent of the nutrition initiative continues to be the provision of nutrition interventions that improve the health status of PLWHA.

### **Substance Use-Related Services**

- A re-solicitation was recently released for funding to support comprehensive health care and support services in substance abuse treatment settings as well as outreach, HIV testing, and transition to drug treatment services for active substance users who are not in drug treatment. Unfortunately, the funding available to be awarded through the re-solicitation has been reduced by \$1.4 million due to the loss of Office of Alcoholism and Substance Abuse Services (OASAS) funding that was previously directed to the AIDS Institute for the initiative.
- The AIDS Institute, other units within the NYS DOH, and the NYS OASAS are discussing how best to promote the federal Substance Abuse and Mental Health Services Administration's (SAMHSA's) Screening, Brief Intervention, and Referral to Treatment (SBIRT) initiative to make screening for substance abuse a routine part of medical care and to identify and treat problems early. Medicaid reimbursement for SBIRT is being implemented.
- As stated above, a buprenorphine mentorship program was recently established to increase the number of clinicians prescribing buprenorphine in upstate New York, and buprenorphine was added to the ADAP formulary in 2008. The number of buprenorphine prescriptions annually increased substantially in 2007 and 2008.

## **Legal Services**

- In late 2009, the AIDS Institute will re-solicit funding for legal services, with a focus on services for both families and individuals.

## **Housing**

- Through the New York New York III initiative, housing will be made available to PLWHA in NYC. This expansion of housing services in NYS may enable grant funds that are currently directed to NYC to be redirected to expand housing services in upstate regions.
- State legislation was proposed in 2009 providing that PLWHA in emergency shelter facilities or living in housing which is receiving monetary aid shall not be required to pay more than 30 percent of household income toward cost of living. The bill passed the State Senate by a vote of 52 to one and was sent to the Assembly.
- The AIDS Institute is involved in discussions with other agencies regarding modifying the eligibility criteria to enable some persons who have HIV (not AIDS) to be eligible for housing in NYC.

## ***Population-Specific Issues***

### **Adolescents and Young Adults**

- The Department's Adolescent Sexual Health Work Group is a joint venture between the AIDS Institute and the Center for Community Health. The purpose of this work group is to ensure that every adolescent achieves optimal sexual health. It seeks to increase adolescent access to and utilization of quality sexual health care services; improve health care provider practices related to promoting optimal adolescent sexual health in the context of comprehensive health care; and engage stakeholders, including young people, in developing public health best practices and coordinated implementation to support optimal adolescent sexual health. The work group sponsored a symposium in February 2009 to plan for future directions of the state's programs targeting this aspect of young people's lives. The work group also developed "Guiding Principles for Adolescent Sexual Health," a document which will be made broadly available to community providers. As a result of the work group's activities, the sexual health education and service needs of young people are now viewed holistically and program models supported through AIDS Institute and other DOH funds will address HIV infection, STDs and unintended pregnancy. In addition, all funded programs will take a youth development, strength-based approach in their work with young people. This holistic and strength-based approach toward adolescent sexual health is reflected in a request for applications released by the AIDS Institute in August 2009 and a solicitation for teen pregnancy prevention and STD/HIV prevention that will be released by the Center for Community Health in 2010.
- The AIDS Institute has established a Young Adult Consumer Advisory Committee (YACAC) to provide input and recommendations on the HIV health care needs of HIV-positive young adults and programs targeted to this population. The group's input has resulted in the development and refining of educational materials for young adults, including the hard of hearing, as well as those with substance abuse or alcohol problems. YACAC members have also provided recommendations on adolescent and transitional care clinical guidelines, participated in community activities, including creating a leadership program to talk about the realities of living with HIV/AIDS with elementary school, middle school, high school and college students, and provided input on several HIV prevention and quality of care initiatives. The group is also harnessing the power of the internet and social media to get reliable information out to peers to help fight HIV/AIDS stigma and discrimination. General HIV/AIDS information has been disseminated via the internet and through live, interactive chat rooms.
- Programs serving children and youth will be examined to address reduced need for pediatric care due to declining numbers of children living with HIV/AIDS and increased need for services for adolescents and young adults.

## **Communities of Color**

- AIDS Institute programs continue to target and reach communities of color. All AIDS Institute solicitations ensure our programs are targeting these communities. About 80 percent of those served through AIDS Institute contracts are persons of color.
- AIDS Institute contracts include requirements related to cultural and linguistic appropriateness of services.
- The AIDS Institute has continued to provide approximately \$700,000 annually to Native American agencies to meet the HIV prevention and support services needs of their communities. In 2009, specific discussions began on a more focused approach to meeting the needs of lesbian/gay/bisexual/transgender (LGBT) Native Americans.

## **Immigrants, Migrants and Seasonal Farm Workers**

- The AIDS Institute makes available “Building Bridges to Cultural Competency,” a one-day training that explores the broad definition of culture and its relationship to competent and effective health care and human service delivery.
- AIDS Institute staff continue to work with the NYS HIV Prevention Planning Group (PPG) Immigrant/Migrant Committee and Statewide AIDS Services Delivery Consortium (SASDC) members to explore and identify ways to meet the needs of immigrants and migrants.
- In response to evolving issues on HIV/AIDS in the immigrant, migrant and seasonal farm worker population, in the summer of 2009, SASDC formed a workgroup comprised of members with extensive and varied experience with these populations. The initial population of focus has been the immigrant population. The SASDC workgroup is committed to working toward heightened awareness of the needs of immigrant populations by networking and collaborating statewide with partner organizations to educate on HIV/AIDS in immigrant populations/subpopulations, increase understanding of legal issues that are barriers to care for these populations, and clarify myths/facts related to the provision of care. The intent of the work group is to impact structural policies and direct services.
- The AIDS Institute has funded and will continue to fund providers that reach migrants and seasonal farm workers.
- The AIDS Institute helps promote events, such as Latino HIV Testing Month and Asian and Pacific Islander HIV/AIDS Awareness Day, to reach immigrants and offer HIV testing, as well as access to care and support services.

## **Individuals involved in the Criminal Justice System**

- The AIDS Institute’s Criminal Justice Initiative contracts with 15 agencies throughout the state that provide the following services system-wide: (1) HIV prevention education; (2) HIV training of peer educators; (3) HIV counseling and testing; (4) HIV support services; and (5) HIV/AIDS transitional planning. A review of the Criminal Justice Initiative and the development of a re-solicitation responsive to identified needs is underway.
- The Hepatitis C Continuity Program makes it possible for treatment for Hepatitis C to be initiated within the Department of Correctional Services (DOCS) without regard to the expected incarceration time remaining, since arrangements for continuity of treatment after release are possible. It enables inmates who initiate treatment prior to release to receive timely referral to appropriate clinics for continuation of treatment.
- There is a Continuous Quality Improvement (CQI) program in place for HIV care at DOCS facilities. Quality results are made available to DOH. DOCS and DOH have ongoing collaborative efforts to improve care.
- The AIDS Institute participates in interagency efforts to enhance inmate access to Medicaid and other public benefits upon release through activities such as training of Department of Correctional Services and Division of Parole staff and implementation of a legislatively authorized Medicaid pilot.
- The AIDS Institute is reaching out to local correctional facilities (jails) to promote inmate access to HIV/AIDS care and services during incarceration.

- The AIDS Institute is building the capacity of community providers to serve the formerly incarcerated through the development of a new training titled, “Improving Health Outcomes for HIV-Positive Inmates who are Transitioning to the Community.” This training was rolled out statewide in July 2008 and informs health and human service providers working with the formerly incarcerated about the culture of corrections as it relates to HIV-infected inmates’ needs upon community re-entry.
- The AIDS Institute has developed a 24-module training guide to assist HIV peer educators located in State correctional settings to train other inmates on HIV and related issues. These materials have also been translated into Spanish. Three booster modules were developed in early 2009 and cover the following topics: 1) mental health, trauma, family reunification; 2) viral hepatitis; and 3) navigating the health care system. The AIDS Institute has also worked to improve training materials used to train correction officers in local jails. Training curricula were developed and pilot tested in conjunction with five local health departments. Evaluation data and debriefing with local health departments and county jail staff indicated that the materials were effective. The training materials have been posted on DOH and Commission of Corrections websites.

### **Individuals with HIV/AIDS and Co-Occurring Conditions**

- Program models within health care initiatives are being reviewed and modified to incorporate prevention and treatment of co-occurring conditions, such as cardiovascular disease and diabetes, and models that are responsive to the needs of an aging population.
- AIDS Institute staff are actively engaged in analysis of Medicaid data to examine the extent and impact of co-occurring conditions among Medicaid beneficiaries with HIV/AIDS. This analysis will inform program and policy development.

### **Mature Adults**

- The AIDS Institute will hold a forum -- HIV & Aging: Red Ribbon, Silver Threads: Healthy Aging in the Era of HIV/AIDS – on December 7, 2009. The purpose of the forum is to elicit input and recommendations from the community and stakeholders. The recommendations will be translated into an action plan to inform the Institute’s response to an aging population with HIV/AIDS.
- The AIDS Institute is engaged in an ongoing review of literature and data pertaining to older adults and has begun discussing collaboration with the NYS Office for the Aging and the NYC Office for the Aging.

### **Men Who Have Sex With Men (MSM)**

- In recognition of the continued impact of HIV infection and STDs on gay men/men of color who have sex with men, the AIDS Institute has issued an RFA to support HIV/STD prevention and related service programs that target the population. The amount of funding to be awarded through the RFA is an increase in the amount currently supporting programs for gay men/MSM.
- The AIDS Institute and the Department’s Bureau of STD Control continue to coordinate with CBOs and local health departments to offer STD/HIV screening at upstate bathhouses and to conduct intensive outreach to other venues that attract MSM, especially those of color.

### **Lesbian/Gay/Bisexual/Transgender (LGBT)**

- In 2008, the AIDS Institute assumed management responsibility for the LGBT Health and Human Services Initiative. This initiative, which supports 46 programs throughout the state that work to increase and facilitate access to health and human services (non-HIV specific) for LGBT individuals and their family members and support systems, had been managed by the Center for Community Health. The AIDS Institute established and staffed the LGBT Health and Human Services Unit in the Division of HIV Prevention. The initiative has become an integral component in the spectrum of services supported by the AIDS Institute, and staff within the LGBT Health and Human Services Unit work closely with the other units in the AIDS Institute that oversee programs that serve LGBT individuals.

## **Working Individuals**

- AIDS Institute efforts to promote employment services include participation in the HIV Welfare to Work Initiative with the NYS Department of Labor and the NYS Office of Temporary and Disability Assistance; the establishment of an AIDS Institute HIV employment work group to highlight the changing realities and needs of PLWHA related to employment; and collaboration with Penn State University, providers, and networks to conduct a study of the vocational development and employment needs of PLWHA in NYS.

## ***Other Concerns***

### **Linkages between health care providers and CBOs and between State and local agencies**

- A recently issued solicitation related to supportive services will encourage improved linkages and communication between health care providers and CBOs.
- The AIDS Institute regularly convenes the Interagency Task Force on HIV/AIDS, which is comprised of numerous State agencies that are involved in HIV/AIDS services.

### **Effective and well staffed consumer advisory boards**

- The AIDS Institute is expanding the PLWHA Leadership Training Institute to add a component involving outreach to PLWHA to expand their meaningful participation in Ryan White HIV Care Networks and other HIV/AIDS planning bodies.
- Consumer involvement continues to be emphasized in planning statewide programs via Ryan White HIV Care Networks, the HIV Prevention Planning Group, and consumer advisory committees.

### **Streamlined and standardized contractual requirements**

- The AIDS Institute is exploring streamlined, coordinated fiscal requirements and monitoring in order to minimize duplicative requests and the administrative burden on contractors.
- The AIDS Institute is exploring the initiation of a performance-based contracting pilot with the goal of moving to performance-based contracting for some HIV/AIDS services.

### **User-friendly data systems**

- The AIDS Institute has been soliciting feedback from AIRS users on reports and functionality that would be most helpful in supporting effective client care management and agency level data management. The next full release of AIRS, scheduled for later this Fall, will include some preliminary reports based on the feedback received. These reports use a Crystal Reports interface with AIRS data and include graphics and drill-down capability. More such reports and some basic custom or ad-hoc reports will be added to the system during 2009 - 2010. Changes are being made to the software to make Counseling and Testing data entry and navigation between screens faster and more efficient. Two enhancements for counseling and testing have been released, and further changes will be released as they are completed.
- Readers are encouraged to relay specific concerns and suggestions for reports or changes to the software via the AIRSNY.org website "modification and enhancement request" interface. The AIDS Institute also sponsors monthly User Group meetings, one in person in NYC and a second via the internet. Feedback from these meetings is used to prioritize upgrades and changes to AIRS. Information and registration for these meetings and regular news updates are available on the AIRSNY.org website.
- The AIDS Institute, in collaboration with the University of Rochester, continues to offer training on use of AIRS data for evaluation. In addition, webinars on optimizing data use and reporting for agency management are planned for the Fall. They will continue in 2010.

### **Stigma**

- The AIDS Institute convened a work group to address the effect of HIV-related stigma on PLWHA. The work group was charged with developing or adapting a social marketing campaign to counteract AIDS stigma and improve the health and well-being of HIV-infected persons. A campaign launch is anticipated in late 2009.

## **VI. Regional Summaries**

This section provides detailed summaries of listening forums held in each region. The summaries include details regarding region-specific concerns, as well as overarching issues and statewide issues, which are also summarized in Section V. As such, the full range of issues and concerns voiced in each region are reflected in this report.

The regional summaries can be used by clinicians, health and human services providers, consumers, Care Networks, and others to identify opportunities to improve programs and services, expand or enhance collaboration, pinpoint unmet needs and bolster needs assessments, and prioritize activities. The AIDS Institute, in its statewide role, has also considered and will continue to consider ways to address or influence these issues.

## Buffalo Region Listening Forums

The following issues were noted by participants in the Buffalo Region listening forums.

### *Prevention*

- **Harm Reduction and Syringe Access:** Opioid overdose prevention, syringe exchange, expanded syringe access, and secondary peer exchange are critically important to minimize disease transmission and maximize health. Syringe exchange programs need flexibility; programs should not be tied to one fixed site. The ESAP would be improved by assuring that participating providers are open and accessible (some turn clients away) and are geographically more widely dispersed. Participants supported the availability of buprenorphine as a prevention strategy.
- **Testing:** The importance of early diagnosis was stressed as there are still people who are unaware of their status. Expanded testing was recommended. A lack of provider familiarity is a barrier to expanded testing. The number and types of testing sites should be maximized. Barriers to testing in emergency departments include overcrowding, an inability to provide confidential counseling, particularly post-test positive counseling, and reimbursement concerns. A pilot program is needed to introduce emergency departments to testing. Participants supported broadening and normalizing testing and noted that it would help minimize stigma and test those who might not come forward on their own.
- **Partner Notification:** There was support for programs that maximize the number of at-risk persons identified and referred for testing and care. It was suggested that there is a need to revamp partner notification services to identify new cases. It was noted that partner notification requires greater collaboration between CBOs and local health units.
- **Integration with STD Services:** Coordination of HIV and STD programs was recommended. It was suggested that county health workers be used more effectively, and a recommendation was made to include both HIV and STD in partner notification. Venue-based STD screening and STD screening in settings where HIV testing is offered were recommended.
- **Prevention Resources:** When prevention initiatives and resources are allocated to address “emerging” populations, it should not be done at the expense of other populations. Increased resources are needed for outreach.
- **Education:** Up-to-date, broad-based education on HIV prevention and care was recommended.
- **Schools:** It was noted that HIV advisory committees in schools are non-existent.

### *Health Care*

- **HIV Specialists:** The number of HIV specialists and sub-specialists in the region is not sufficient. Most physicians refer any patient with HIV to a specialist. Specialists are suffering from “burnout,” and few new physicians are available to take their place. There is a need to incentivize HIV and hepatitis C care. Participants suggested improved options for HIV training for residents to increase the number of residents who opt to specialize in HIV care and improved benefits associated with practicing in rural settings to increase the number of physicians who choose to practice in such settings.
- **Acute Care:** All PLWHA, regardless of residence, must be assured access to care at a local/regionally accessible acute care facility. Local hospitals may not be prepared to care for persons with HIV and frequently refer to tertiary care facilities that are often many hours away.
- **Telemedicine:** While it should not take the place of one-on-one interactions between a patient and a provider, telemedicine should be implemented as an adjunct to traditional face-to-face care for stable patients and sub-specialty consults.
- **Mental Health:** Onsite mental health professionals are needed to increase the likelihood of initiation and retention in care. Mental health care for uninsured persons is limited. Participants noted that HIV-positive patients often suffer from depression, and concerns about medication side effects exacerbate their

depression. More than half of the patients with HIV/AIDS at Erie County Medical Center are in need of mental health services.

- **ADAP:** An increase in the income requirements to be eligible for ADAP is required to assure coverage of the working poor.
- **Hepatitis C:** Enhanced resources for the care and treatment of persons with hepatitis C are needed in the region. Barriers to care and treatment must be minimized. For example, transportation to care settings should be provided. STD clinics should conduct hepatitis C screening.
- **Dental Care:** All persons with HIV/AIDS should have access to appropriate dental care delivered by providers familiar and comfortable with the care and treatment of persons living with HIV.
- **Chronic Disease Model:** It was noted that we need to look at HIV as a chronic disease, and eventually, it will be an internal medicine issue.

### *Health Care Financing and Health Coverage*

- **Provider Education:** Education and information is needed by providers regarding health coverage (e.g., benefits, eligibility, coordination between programs) to minimize staff time dedicated to eligibility determination and coordination of benefits and to maximize the time available for care and treatment. Participants noted the need for education and information on Medicaid, Medicare Part D, and ADAP. Education and training for providers regarding Medicaid is especially important, including spend-down, recertification, prior authorization, limitations on pharmaceutical benefits, etc. Technical assistance and training for case managers on Medicaid and ADAP will help case managers assist clients in the access and coordination of benefits.
- **Managed Care:** Managed care restrictions, such as lack of reimbursement for pre- and post-test counseling, are barriers to care.

### *Supportive Services*

- **Transportation:** There is limited access to reliable transportation, which creates a barrier to care. Prohibitions on travel to sites other than physician appointments are problematic. Some transportation providers require significant advance notice, which is not always possible. Medicaid will frequently only pay for transportation to an emergency department.
- **Case Management:** Case management services should be standardized. Ongoing availability of case management for those in need regardless of life stage (e.g., following return to work) is critical. There is a three-week wait for case management services in Buffalo. Suggestions for alleviating this shortage include reimbursement that is sufficient to support qualified staff, to support sufficient staffing, and to minimize turnover.
- **Housing:** The lack of adequate and affordable housing in the region is a major crisis.
- **Translation/Interpretation:** There is a lack of services for mono-lingual individuals and their families in Latino communities in the city of Buffalo and Erie County in general. In addition, services are needed for the deaf and hard of hearing.

### *Population-Specific Issues*

- **Adolescents and Young Adults:** It was noted that compliance and adherence are significant issues for adolescents. For perinatally infected adolescents, transitioning to adult care is difficult, as is disclosure of status to their partners. Prevention messages must be targeted to young adults and young men of color, particularly for those who may perceive HIV as easily treatable. Messages must reinforce that HIV is not as simple as taking a pill. Drug company advertisements that show beautiful, healthy people are misleading and negatively impact prevention messages.

- **Communities of Color:** Participants noted the need for services designed for Black gay men, outreach to Black men in Batavia, services for Latinos in the Westside community, and services for the Seneca nation reservation.
- **Incarcerated Individuals and Releasees:** Education and training is needed regarding the care and treatment of incarcerated individuals with HIV. Incarcerated persons need access to complete and timely medications consistent with established treatment regimens and information regarding treatment side effects. Releasees need coordinated HIV and hepatitis C care, education regarding Medicaid eligibility, and housing. The AIDS Institute's Criminal Justice Initiative should be replicated in jails.
- **Mature Adults:** It was noted that there are 150 patients at Erie County Medical Center over the age of 50. It was noted that many persons over the age of 50 are also in need of mental health services. The challenges of long term survival include spiritual and emotional quality of life. Disclosure continues to be difficult for many mature adults. The need for hospice and nursing home care should be re-visited.
- **Women:** It was noted that services should be targeted to meet the needs of women, including the need for "safe spaces."

### *Rural Issues*

- **Substance Use Services:** In many rural regions, there is very little or no access to detoxification and substance abuse services. The wait time for services may be as long as several weeks.
- **Isolation and Stigma:** Rural communities are more likely to be prone to isolation and stigma. In addition, rural/suburban populations have no or limited access to nearby services. These needs must be considered as part of the overall service delivery system.
- **Transportation:** Transportation is a significant issue. Bus tokens and gas cards are often insufficient to assure transportation to care and treatment.
- **Provider Education:** Participants indicated that regional health and human services providers are frequently not as well educated in the care and treatment of PLWHA.

### *Other Concerns*

- It was noted that the PLWHA Leadership Training Institute (LTI) is an excellent program. Those newly diagnosed should be paired with an LTI mentor.
- One participant noted that NYC and the rest of the State are two different worlds and stated that the City of Buffalo is a city of families and neighbors. The number of infected persons upstate is far fewer but so are the dollars. Yet AIDS Institute RFAs treat the State as one.
- Poverty is an overwhelming issue that complicates the delivery of services. Buffalo is the second poorest large city in the nation.
- Stigma and discrimination extend to both PLWHA and the providers who treat them.
- People have to navigate an underground tunnel to obtain HIV/AIDS services at Erie County Medical Center, promoting the stigma of shame.
- Requests were made for enhanced data and participants noted that data entry in the AIDS Institute Reporting System (AIRS) is difficult.
- Participants requested consistency from the AIDS Institute in terms of standards, contract management and reporting.

## Rochester Region Listening Forums

The following issues were raised by participants in the Rochester region listening forums.

### *Prevention*

- **HIV Testing:** Participants noted support for universal testing along with streamlined pre- and post-test counseling. It was suggested that HIV testing be “normalized” – it should be something everyone gets. There is a need to get the word out about the importance of early diagnosis and getting people into care. Emergency departments need to do testing, although it was acknowledged that they are crowded and dealing with many issues.
- **HIV and STD Integration:** There should be better coordination between HIV and STD programs. Responsibility for HIV rests with CBOs, while responsibility for STDs rests with local health departments. There should be a way to partner CBOs and local health departments for a focused response. Local health departments do rapid testing, have an impact on changing practice patterns, and can reduce late diagnosis. STD screening and HIV counseling should be a single, unified objective. Treating gonorrhea is a means of HIV prevention. Disparities in STDs need to be addressed. It was indicated that 75 percent of gonorrhea cases among women are in Black women, and 85 percent of cases among men are in Black men.
- **Partner Notification:** Partner notification services should include testing. Participants noted that State procurements should require and emphasize partner notification as part of all prevention activities. There is a need for collaboration among agencies to improve partner notification.
- **Harm Reduction:** Opioid overdose prevention, ESAP, and peer syringe exchange are critical services. It was noted that the opioid overdose prevention program had recently saved a life.
- **PEP:** It was recommended that education on post-exposure prophylaxis (PEP) requirements could increase condom use (i.e., if people were aware that PEP means they have to go to the emergency room and take pills for 30 days, there might be an incentive to use condoms).
- **HIV Prevention Interventions:** It was suggested that DEBIs and EBIs are not particularly useful or practical.
- **Education:** It was noted that fears and misconceptions are back, and it was suggested that there be more general education.

### *Health Care*

- **Mental Health and Substance Use Services:** Participants noted that mental health services, substance use treatment, and detoxification are limited in the region and are most severely limited for those without insurance. Barriers to the establishment of satellite clinics limit the ability to increase access to mental health services in underserved regions. There are few or no mental health providers in the Southern Tier.
- **Access:** Participants noted that all PLWHA, regardless of area of residence, should be able to access care at a local or regionally accessible acute care facility. HIV care should be integrated as a part of general medical care.
- **PEP:** Post-exposure prophylaxis (PEP) is not available at many facilities, and concerns regarding payment result in many not initiating or completing a course of treatment.
- **Hepatitis C:** Enhanced resources for the care and treatment of persons with hepatitis C are needed to ensure early identification and treatment of infected persons, particularly for the mono-infected. Physician incentives for the care of people with hepatitis C are needed. Expanded education on the treatment of dually infected persons will facilitate care and treatment. Screening might be enhanced by encouraging STD clinics to conduct general public hepatitis C screening and screening in jails. Transportation is needed to facilitate access to hepatitis C services. Participants indicated that there is fear of treatment side effects, such as depression, as well as fear of treatment non-response.

- **Dental Services:** There is a need for access to appropriate dental care and treatment delivered by providers who are familiar and comfortable with the care and treatment of persons living with HIV.
- **Provider Education:** Provider education is needed on anal dysplasia and post-exposure prophylaxis. Participants thanked the AIDS Institute for the guidelines on anal human papillomavirus and recommended the development of a “how to” booklet to help institutions initiate the guidelines.
- **Outreach:** It was recommended that more resources are needed for outreach to support going into the community to find people who don’t have a medical home and get them into care.

### *Health Care Financing and Health Coverage*

- **Provider Education:** There is a need for provider education regarding health coverage -- including Medicaid, ADAP, Medicare Part D, and managed care -- related to eligibility, coordination of benefits, prior authorization requirements, limitations in benefits, and interface between systems. Training and technical assistance is needed for case managers on Medicaid and ADAP.
- **Managed Care:** HMOs often do not reimburse providers for pre- and post-test counseling, which adds to the difficulties associated with implementation of testing and case finding in hospitals.
- **Medicaid Reform:** Participants expressed concern regarding Medicaid changes, reimbursement reform, and hospital closures and their impact on Medicaid-funded HIV care and treatment.
- **ADAP:** In order for patients with ADAP to get to the dentist or specialty care, they have to travel to Rochester. More rural physicians should accept ADAP Plus.
- **COBRA:** It was suggested that a COBRA rate increase is needed. Participants noted that it is a struggle to provide services and obtain quality staff with the current rates.
- **Coverage for Dental Services:** It was noted that Medicaid does not fully cover dental services.

### *Supportive Services*

- **Housing:** The lack of adequate affordable housing in the region is a major crisis. A participant noted that often there is no place to send the homeless, aside from the city mission. It was noted that providers should not have to demonstrate a link between housing and medical care since the link has been proven.
- **Transportation:** Participants indicated that the lack of easily available, convenient, reliable transportation, especially across county lines and in rural areas, is a significant barrier to accessing care and treatment. There is concern regarding the quality and consistency of transportation services. Transportation to specialty care is problematic. Transportation requirements and limitations are problematic. The requirement for prior approval to cross county lines creates barriers. Prohibitions on travel to sites other than physician appointments are problematic. Some transportation providers require significant advance notice, which is not always practical or possible. Medicaid will frequently only pay for transportation to an emergency department, which is part of the reason why the emergency department is the medical home for many. Addressing distance improves retention and adherence.
- **Translation and Interpretation:** Licensed interpreters are needed as there is a large deaf population in the region.
- **Legal Services:** It was noted that legal services impact care and should be provided onsite at medical providers.

## *Population-Specific Issues*

- **Persons with Co-morbidities:** Serving individuals with co-morbidities requires close collaboration among multiple State and local agencies, including OASAS, DOH, and the Office of Mental Health (OMH).
- **Communities of Color:** HIV-positive Native Americans must be provided outreach and care that is culturally sensitive (e.g., condom use is contrary to traditional beliefs). An urban Indian health clinic is needed. Beliefs and cultural issues in African American and Hispanic populations must be considered. Innovative models are needed to get people in the African American community to look at this issue differently. It was noted that resources are needed to respond to the upward trend of African American men becoming infected with HIV and STDs.
- **Releasees:** Follow-up hepatitis C treatment for persons released from correctional facilities must be enhanced to assure that no person is lost to follow up. It was noted that a major issue faced by releasees is the timing associated with reactivating Medicaid.
- **Deaf and Hard of Hearing:** Rochester has one of the largest per capita deaf and hard-of-hearing populations in the United States. There is increased demand for interpretation and translation services for this population.

## *Rural Issues*

- **Access:** Rural and suburban populations have no or limited access to nearby services.
- **Provider Education:** In rural areas, there must be education of providers, including primary care physicians, emergency room physicians, physician assistants, and nurse practitioners.

## *Other Concerns*

- It was noted that there is a need for enhanced access to data with which to evaluate trends, identify gaps in care and services, and develop effective responses. The Rochester Mortality Study was noted as a tool that could not be fully implemented as a result of data limitations. Some participants noted that AIRS is difficult to use. Participants expressed difficulty in matching State and county (Monroe) data. Some suggested that AIRS and HIVQUAL must communicate better with each other.
- Participants indicated that coordination and collaboration among CBOs are critical. Collaboration might increase testing sites, thus reducing late diagnosis and increasing the proportion of people with HIV/AIDS who are aware of their status. It was recommended that requirements for coordination be included in requests for applications and that local health departments be utilized more.
- Some participants indicated that a comprehensive resource directory would be beneficial.
- It was recommended that reporting be consolidated for those agencies with multiple AIDS Institute contracts with consistent data reporting elements and timeframes. A participant noted that the amount of time spent responding to contract managers is excessive.
- CDC reporting requirements are troublesome, particularly in terms of the transmission categories and the large proportion of cases that are identified as No Identified Risk (NIR). It was suggested that the majority of new infections are related to heterosexual behavior and that a formal study be done of the NIR cases in the community.
- Funding was requested for research on bi-sexual African Americans, integration of HIV and STDs, and effective behavioral interventions.
- It was suggested that providers could better serve persons living with HIV if there were improved coordination among the State DOH, OASAS, the Office of Mental Retardation and Developmental Disabilities (OMRDD), DOCS, and OMH.

## Syracuse Region Listening Forums

The following issues were noted by participants in the Syracuse Region listening forums.

### *Prevention*

- **Harm Reduction and Syringe Access:** Participants noted that more, and more widely geographically dispersed, Expanded Syringe Access Program (ESAP) pharmacies are needed. Participants noted that some pharmacies are not user friendly and even turn clients away. Additional education is needed for these pharmacies. Increased access to substance abuse services including methadone maintenance (particularly in Oneida) and detox programs as well as buprenorphine therapy was cited as essential to a successful harm reduction/prevention strategy in Central New York.
- **Testing:** The need for expanded HIV testing was identified. Participants suggested maximizing testing in emergency departments; integrating HIV testing with HCV testing and treatment; making testing available in venues that provide medical, dental, substance abuse and mental health services; offering testing in locations that are convenient for individuals unlikely to utilize medical services; maximizing referrals between CBOs and testing sites; and maximizing the use of rapid tests. It was noted that the misunderstanding of what constitutes appropriate counseling and a lack of understanding and trust remain barriers to HIV testing. This must be combated through conveyance of accurate and up-to-date information. Barriers to testing in the emergency department include overcrowding; a misconception concerning the amount of staff time necessary to conduct required counseling; lack of reimbursement and the cost of test kits. Funding for test kits was suggested. Some participants also expressed the desire to mandate the offer of HIV testing and referral to necessary services as a part of routine medical care.
- **Education:** The need for up-to-date, broad based HIV prevention and risk reduction education was emphasized. Specific reference was made to the need for educational and outreach efforts targeted at Black MSM; the Latino population; the Sudanese; seniors particularly Russian and Chinese immigrants; adolescents and perinatally infected youth; Native Americans; the deaf and blind; inmates; and traditionally marginalized populations. School districts must develop and implement effective HIV prevention education programs.
- **Integration of HIV prevention with HCV, STD and Substance Abuse Services:** The need for incorporating HIV prevention education into hepatitis C, STD and substance abuse programs was emphasized.

### *Health Care*

- **HIV Care/Specialists:** Participants noted that there is a shortage of physicians providing HIV/AIDS care, particularly in rural areas. Internal medicine and family practitioners are not doing HIV care. Waiting lists are causing long delays in receiving care. This, in conjunction with the difficulties in accessing transportation and transportation costs, contributes to individuals not seeking care on a regular, ongoing basis. Shortages will likely get worse because physicians are leaving the area and there are not enough new practitioners in the “pipeline” to replace them. Residency programs are needed to expose students to HIV care. It was suggested that a team of primary care and medical specialists travel to rural areas and hold an “open day” to increase access to needed services. Additional HIV training for physicians practicing in rural areas may be helpful in addressing current shortages. The promotion of telemedicine and satellite conferencing for education may assist rural areas. The deaf, Native Americans and migrant workers were identified as populations that often fall through the cracks. Participants advocated for standards of practice to be enhanced to include anal paps for HIV-positive patients. Education is needed for medical providers on culturally competent care. Services must be provided in locations and at times convenient to target populations. PLWHA often do not have enough sick or leave time to cover medical visits. Patient education on the side-effects of medication is needed.

- **Acute Care:** Participants stressed the importance of the services delivered by the Designated AIDS Centers (DACs) but reported that hospital administration often does not respond to the DAC's needs. The DAC does not have staff levels appropriate to its caseload. Specific reference was made to case management staff that must manage 250+ patients (later corrected to 350 patients per case manager).
- **Mental Health:** Comprehensive access to mental health care is critical, including the availability of mental health clinicians and counselors for all persons regardless of health coverage.
- **Hepatitis C:** It was noted that enhanced resources for the care and treatment of persons with hepatitis C are needed in the region. Free or low cost testing is needed. Coordination and integration of HIV, STD and hepatitis C care is critical in assuring accessibility in rural areas and to assure programmatic and fiscal viability and effectiveness.
- **Dental Care:** All persons with HIV/AIDS should have access to appropriate dental care. The number of dental providers enrolled in ADAP Plus and/or Medicaid is not sufficient to meet the demand. It was suggested that allowing private dentists to become ADAP Plus providers may help address this gap.
- **Long Term Care:** It was noted that there is very limited availability of nursing home beds in the 17-county region surrounding Syracuse, resulting in long travel distances between a person's (and their family's) home and the long term care facility. Participants noted that there are waiting lists which cause individuals to remain in acute care facilities for extended and not medically necessary days. Long term care facilities may not be willing to accept HIV patients given the relatively high costs of care resulting from expensive treatment regimens.
- **Chronic Disease Model:** It was noted that models of care and services continue to reflect HIV as an acute disease rather than a chronic, long term condition.

### *Health Care Financing and Health Coverage*

- **Reimbursement Issues:** Participants indicated that, in addition to low reimbursement rates paid under Medicaid, ADAP and ADAP Plus, program restrictions also impede access to appropriate care for PLWHA. For example, ADAP will not pay for procedures such as colonoscopy or anal pap smear. Adequate reimbursement rates for both the procedure and physician services must be established. Funding should also be made available to expand rapid testing in private medical settings. Increasing co-pay levels are a barrier to care.
- **ADAP:** Participants noted the need for education and information on ADAP.
- **Managed Care:** Participants indicated the need to clearly define the requirements to be considered an HIV specialist for managed care organizations and supported access to the full spectrum of quality HIV services in a managed care environment. They asked for assurances that managed care plans would allow DACs to act as primary care providers and that the enrollment process is completed by social service staff aware of and sensitive to the care needs of persons living with HIV infection.

### *Supportive Services*

- **Transportation:** Because of significant travel distances and the rural character of much of this region, the limited access to reliable transportation services was cited. The lack of alternatives when Medicaid funded transportation is limited or not available is an issue. Some individuals must travel over 160 miles one way for an appointment. Bus tokens are provided but some clients need to transfer three times. The result is that many clients forgo their appointments. Participants also identified the need for transportation to non-medical visits such as support groups, network meetings and educational sessions as important to increased participation by PLWHA. Transportation deficits in Binghamton and rural areas were specifically cited.
- **Case Management:** A number of participants identified case management as an important issue. There is frequent turnover of case managers that affects the continuity and coordination of care and services for PLWHA. Non-competitive salaries and high caseloads contribute to this turnover. It was noted that

COBRA case management is in jeopardy. Hiring standards are prohibitive given the limited candidate pool in central New York and the salary level. Additional culturally appropriate, fairly compensated case managers are needed particularly in rural areas where the case manager may be the only person aware of a PLWHA. More creative approaches toward case management are required. Case managers should focus on the individual and address his/her long-term needs including exploring skill development and return to work. With an aging PLWHA demographic, more focus should be given to senior issues.

- **Housing:** There is a shortage of housing in the region. People on a fixed income find it difficult to secure affordable housing and there is a waiting list for subsidized housing. At the time of the forum, HOPWA had a waiting list of 70 that may take up to two years to exhaust. The city of Syracuse needs better transitional and permanent housing. The need for assistance to PLWHA for energy costs was also noted.
- **Translation/Interpretation/Literacy:** Services for the deaf population residing in Syracuse must be assured. The lack of literacy in portions of rural New York challenges treatment compliance. Literacy in the Latino community is a significant concern in the Syracuse region requiring focused attention, education and training.
- **Support Services:** Support services and assistance in socialization must be integrated into the lives of PLWHA. Individuals continue to require social supports long after their infection is under control; support services are also essential for adherence to treatment and retention in care. A need for support from peers is an ongoing and critical need regardless of degree of health or sickness, dependence or independence. The following needs were identified: support groups to strengthen adherence; drop-in centers providing social activities and informal support; programs for youth and the over-50 population; social opportunities that make PLWHA feel part of the community; and support services designed for the blind and deaf. The lack of opportunities for socialization in Binghamton and Utica (also cited for an overall lack of support services) was specifically mentioned.
- **Nutrition:** It was noted that a nutritional diet is essential for PLWHA and it is important that consumers understand this and that providers routinely assess nutritional status. Services such as congregate meals must be maintained and expanded where practicable. However, because of the extensive geography and transportation limitations in CNY Region, more creative approaches must be employed. Meals-on-wheels, for those who qualify and food vouchers are alternatives. A mobile food pantry was suggested. Limitations and reductions in nutrition programs were noted as a deficiency. Issue was taken with the AIDS Institute/Ryan White process of “graduating” PLWHA out of congregate meals with the hope of moving them toward independence. This effectively prohibits clients from experiencing the social opportunities associated with meal programs.
- **Treatment Adherence:** Specialized treatment adherence services are needed for substance users and people with mental illness.
- **Legal Services:** There is great need for legal services, particularly for people without children.

### ***Population-Specific Issues***

- **Adolescents:** It was noted that enhanced outreach and case identification is required for this group. The transition from pediatric to adult care is often difficult. For adolescents who have been taking medication all their lives, special attention is needed to ensure ongoing treatment adherence. Service providers must support efforts to promote testing and reinforce the importance of prevention and treatment compliance. Young adults frequently present at agencies pregnant, an indication that the safe sex message is not effective. All service providers must recognize that issues related to disclosure are extremely important to this population.
- **Pregnant Women:** A question was raised regarding the appropriate response when an infected pregnant woman chooses not to receive treatment, thus knowingly placing her unborn child in danger. It was noted that the first positive baby in the region in ten years was born two years ago as a result of a mother who refused care. Participants identified family therapy as a much needed service that must continue to be funded.

- **Children:** Participants emphasized the need for ongoing support for infected children despite the fact that their numbers have greatly diminished.
- **Individuals over the Age of 50:** Individuals in this subpopulation have unique needs and require dedicated services; however, such services are limited in the region. Attention must be paid to those recently re-entering the dating scene. Case management specifically tailored to the needs of older individuals with HIV infection is needed. Information and education geared to this population regarding HIV as a chronic disease, its long-term implications, and HIV medication side effects was requested. Supportive services specifically designed for persons over 50 are critical.
- **Working Individuals:** Employed individuals have no access to case management services despite continuing need. For many PLWHA who are employed, the lack of available medical and support services creates a barrier to care. These services are frequently provided only during work hours. Service provision after hours would enable many more individuals to access these services. Worker re-training would prepare individuals to continue to work while living with HIV infection especially if their infection has necessitated a change in profession.
- **Migrant Workers:** Participants indicated that more focus is needed on the medical and support service needs of this population.
- **Native Americans:** It was noted that Native American people often fall through the cracks. In general, Native American individuals do not wish to acknowledge or talk about HIV. There is a noted lack of collaboration between Native American and other service providers. Native Americans are visual learners and Native American women are the best vehicle for teaching in this community. Education strategies must reflect this. Enhanced prevention education was strongly recommended. Cultural competence is important to engender trust.

### *Rural Issues*

- **Transportation:** The availability of reliable transportation services in rural communities must be ensured because clinical care sites may be many miles away, across county borders and otherwise difficult to access, particularly when ill.
- **Enhanced Services:** HIV prevention, care and treatment services are needed in underserved areas. Utica was specifically referenced, as were Delhi, Otsego, and Oneonta.
- **Case Management:** Case managers play a critical role in rural communities. Often, the case manager may be the only person aware of an individual's HIV status and, therefore, is the only one able to provide assistance in accessing care and treatment. It was noted that low rates of reimbursement and high staff turnover have compromised the effectiveness of case management in these communities
- **Access to Care:** It was suggested that a team of primary care and medical specialists travel to rural areas and hold an "open day" to increase access to needed services. Out-stationing of providers would enhance access to mental health, substance use treatment and treatment adherence support services in rural communities. It was suggested that home visits could also be used to assess whether the client has enough food, if his/her house is properly heated, and to reinforce the need for treatment adherence.

### *Other Concerns*

- Participants indicated that the central New York region has experienced a surge of new, needy patients. Some are very sick exhibiting pneumocystis pneumonia and opportunistic infections.
- Despite exhaustive efforts to educate consumers, providers, clinicians, and the public, the stigma of HIV/AIDS remains. This stigma impedes diagnosis and treatment and can lead to social ostracism.
- Participants cited a potential New York Association of County Health Officials (NYSACHO) position in support of legal action against infected individuals spreading the disease as a barrier to testing. People believe if they are found to be HIV positive, they may have to go to jail.
- Clinicians have advocated for the ability to test a comatose person if they are the source of a needle stick.

- Providers expressed concern that time consumed by excessive documentation and reporting required by the AIDS Institute reduces the available time to serve clients. They indicate that requirements of other agencies are fewer and less cumbersome.
- There is a need to improve coordination among OMH, OMRDD, OASAS, and the AIDS Institute.

## Albany Region Listening Forums

The following issues were noted by participants in the Albany Region listening forums.

### *Prevention*

- **Harm Reduction:** Syringe exchange programs are needed greatly in both Albany and Schenectady where a high rate of HIV infection is attributable to injection drug use.
- **Testing/Case Identification:** Participants advocated for increased HIV testing and case finding activities. Several issues concerning HIV testing were raised including: the need for expanding HIV testing and counseling throughout the region targeting all high-need populations (Saratoga County and the North Country were specifically mentioned); increased testing options for the uninsured (testing for the uninsured in Fulton/Montgomery counties is only available by appointment at a local hospital, and is not available in Spanish); testing sites that are culturally and linguistically appropriate to the local population; and additional funding to assure the availability of rapid testing. Additional funds should be provided for testing for the uninsured and to local health departments to expand rapid testing capabilities. Rapid testing should be made more accessible outside Albany. The Saratoga County Health Department noted numerous requests for anonymous rapid testing, yet there are currently no sites in Saratoga. Testing should be available on a walk-in basis. Counseling and testing should be offered in substance abuse treatment facilities and treatment programs for mentally ill chemical abusers (MICA). Efforts should be made to increase screening and testing among adolescents, females, persons of color, men who have sex with men, intravenous drug users, the homeless, and older adult populations. Participants emphasized that testing should remain voluntary with consent.
- **Education/Outreach:** The need for outreach and prevention education was clearly voiced. Sexual transmission, elimination of risky behaviors, condom use and other primary and secondary prevention must be stressed. Consumers should help shape these efforts by participation on consumer advisory boards and by becoming politically active. It was suggested that public service announcements (PSAs), such as those commonly used in the NYC region, would be effective in the Northeastern New York Region. PSAs would give HIV/AIDS a more visible presence and increase overall awareness. Community and school -based approaches that reinforce prevention should be encouraged. Outreach in which HIV is the subtext was advocated as a means of reaching those who will not themselves seek testing. Substance abuse and MICA treatment facilities were identified as high priority settings for HIV prevention education. Support for prevention education programs targeted toward these facilities should be sustained. Participants identified MSM, individuals over 40, and adolescents as populations in need of outreach and prevention education.
- **Integration of HIV with STD Services:** Participants indicated that the HIV Partner Assistance Program (PNAP) is important in identifying at risk persons and referring them for testing, care and treatment. Coordinating STD and HIV partner notification would markedly improve the impact of both programs and make more effective use of the limited county health workforce. It was noted that because HIV is not considered an STD, parental consent is required for treatment, and this can be a significant barrier to care.

### *Health Care*

- **Health Care Provider/Specialist Shortage:** Participants noted that there is a shortage of dental, medical, substance abuse, and mental health providers familiar with the special issues facing PLWHA In the Northeast Region, particularly in rural areas. It is difficult to find HIV specialists and other providers who are qualified. Students do not seem interested in HIV, and there are few new clinicians entering HIV care, suggesting that shortages will be ongoing. It was noted that there is need for an increased number of health care providers that are familiar, trained and comfortable with the care and treatment of persons living with HIV. The availability of specialty care providers who accept Medicaid and ADAP Plus and

are trained to diagnose and treat HIV-specific problems is crucial. The need for specialists in the areas of dermatology, urology, and ophthalmology were specifically mentioned. Reimbursement levels under ADAP Plus and Medicaid discourage providers from treating PLWHA. The shortage of providers has led to excessive waiting periods for appointments, which creates a barrier to retention in care and treatment adherence. This is particularly the case in rural areas where providers are even less available, and travel distances and transportation issues present further obstacles.

- **Acute Care:** To assure that all persons living with HIV are able to access care at a regionally accessible acute care facility, it is vital that local/rural hospitals are well equipped to provide quality care for persons with HIV. It was suggested that establishment of DAC extension clinics would significantly improve overall health outcomes that are compromised by limited availability of transportation in rural counties.
- **Mental Health:** Participants noted that mental health care and psychosocial support shortages are considered a significant barrier to care. While the need is great, the available services are inadequate. This is particularly the case in rural areas, where participants indicated that mental health support is often limited to a five-minute consultation during the writing of a prescription. Mental health needs are often related to addiction disorders and depression. Individual mental health, drug and alcohol treatment is needed greatly. It was noted that Hudson Headwaters Health Network integrates mental health services into primary care visits. Listening forum participants indicated this approach is effective and has reduced no-show rates by 80 percent. Participants also stressed the importance of having a mental health workforce linguistically and culturally compatible with the community served.
- **Dental Care:** Participants noted that the lack of sufficient dental services in this region has been a long-standing and serious issue. The lack of proper dental care has compromised the ability of many individuals to eat properly and satisfy their nutritional needs. There is not an adequate number of dental providers that accept ADAP Plus or Medicaid. It was noted that while this is a shortage throughout the area, dental services are extremely scarce in the North Country.
- **Integration of Care:** In order to provide comprehensive, individualized care for PLWHA, participants recommended the integration of HIV/AIDS services with primary care, mental health care, substance abuse services, and STD and hepatitis C treatment services. Continued attention must also be given to coordination and communication between the DAC and community based service providers. Community based organizations (CBOs), AIDS Service Organizations (ASOs) and testing centers must maintain effective referral systems to ensure that all appropriate testing is performed. Participants indicated that they often struggle with the existing system of referral and follow-up. The reluctance of some governmental agencies to cooperate with others was identified as a barrier to coordination and integration of care.
- **Access:** Services must be provided in locations and at times convenient to target populations. PLWHA often do not have enough sick or leave time to cover medical visits.
- **Education:** It was noted that education is needed for medical providers on culturally competent care. Patient education on the side-effects of medication is needed.
- **Health Disparities:** Participants emphasized that health disparities must continue to be addressed, especially in times of constrained budgets and fiscal uncertainty. They emphasized the need for individualized health services that take into account people's culture, beliefs, and spirituality.

### ***Health Care Financing and Health Coverage***

- **Reimbursement Issues:** The adverse effect of ADAP and Medicaid reimbursement restrictions on access to care was a major concern noted during the forum. The number of Medicaid and ADAP providers must be expanded. This can be accomplished by increasing reimbursement under these programs. It was noted that COBRA programs are losing money every year, and their rates should be increased. Participants suggested that if these programs close, a plan is needed to replace case management services.
- **DAC Reimbursement:** Albany Medical Center's (AMC's) DAC plays a critical role in the care of PLWHA in this region. With a greater proportion of care delivered on an outpatient basis, inpatient

revenues, which are critical to the DAC's viability, will continue to erode. The impact of Medicaid reform and the soon-to-be-implemented mandatory Medicaid managed care are also of concern. Participants advocated for enhanced reimbursement for the DAC. Participants expressed concern that, in the absence of reimbursement incentives, AMC may not continue as a DAC.

- **Coverage Issues:** Participants suggested that income limits for ADAP eligibility should be raised, thus opening the program up to more people. Health coverage for the uninsured was cited as a barrier to care. A participant noted that Medicaid limitations on coverage until "one exhibits 18 months of clean time" must be reassessed to facilitate entry into needed care.

## *Supportive Services*

- **Transportation:** There is universal concern over the lack of adequate transportation in the region and the barrier it presents to care. Participants indicated that it has been the region's number one priority for the last decade. While transportation provided under the Ryan White program does work fairly well in the three urban areas of the Capital District, participants at the listening forum indicated that scheduling through the case manager is sometimes problematic. Although participants were clear that the Ryan White program is not intended to be an emergency transportation system, the fact that it is not available for emergency transportation was considered a shortcoming. It was noted that the program does not work as well in rural areas because these areas lack an adequate transportation infrastructure and are medically underserved. The long travel distances/times to urban medical facilities and service providers are difficult because of the lack of transportation options; severe winters further complicate the issue. If transportation is available, its expense can be prohibitive. Medicaid transportation is often the only alternative. Restrictions placed on inter-county Medicaid transportation by county social services departments were specifically identified as barriers. Specific examples of the transportation issues referenced above were cited for Columbia, Greene, Fulton and Montgomery Counties. One participant noted that "we have to jump through fiery hoops to get transportation." The lack of transportation available to case managers who often must travel great distances was also seen as barrier. A recommendation was made to increase the amount of Ryan White funding for transportation in the region.
- **Housing:** The shortage of decent, safe, affordable housing in good neighborhoods is a serious and persistent problem in this region. Housing is available in urban areas, but not in neighborhoods that are good for clients. It was noted that there is a shortage of HOPWA (Housing Opportunities for Persons with AIDS) funding in the Albany eligible metropolitan statistical area (EMSA) (Albany, Schenectady, Rensselaer, Saratoga and Montgomery Counties). It was stated that demand is so high and waiting lists so long that referrals are no longer being taken. Some participants suggested that an upstate version of NYC's HIV/AIDS Service Administration (HASA) be established to manage housing issues and expand housing opportunities.
- **Case Management:** Participants cited the need for improvement in case management and indicated that it is the link to medical services and improved outcomes. Case management is critical for client advocacy, care coordination, linkage to vital services and improved outcomes. It was noted that in rural areas, case managers are frequently the only individuals aware of PLWHA. Participants identified a need for additional culturally competent case managers that are reflective of the populations they serve. They specifically advocated for COBRA case management. It was stated that COBRA programs are losing money every year, and if COBRA programs close, a plan is needed for the delivery of case management services. With the movement toward a medically oriented model of care, more medical and pharmaceutical education is necessary. Medical supervision/consultation is also required. Case managers must receive training so that they become more conversant with clinical, pharmaceutical, and laboratory aspects of HIV/AIDS. Case managers must frequently travel to the client to assure confidentiality and/or because the client is too ill to travel. Therefore, transportation must also be available for case managers, particularly in rural areas. Additional monies are needed to support an adequate number of qualified case managers.

- **Cultural and Linguistically Competent Services:** Participants identified the need for culturally and linguistically competent services. The need for additional bilingual mental health workers and Spanish-speaking clinicians was identified. It was noted that there are only a few bilingual staff at Albany Medical Center.
- **Support Services:** Concerns were expressed regarding the shift to more medically oriented Ryan White-funded supportive services. Several individuals noted that while the medical model is important, it must be supplemented to assure the best possible patient outcomes. The movement to a medical model was criticized due to limitations in funding for support services and the requirement that all approved services must have a documented link to improved medical outcomes. Participants advocated for community-based support services and believe that without them, medical care cannot be successful. Further, as a result of changes in Ryan White prohibitions, service gaps are emerging. A plea for greater flexibility in the use of funds was requested. Participants expressed the need for continued support of peer and social support services sensitive to the language and culture of special populations in the region. These services, particularly peer support, can assist PLWHA to move toward self-management. The pediatric, youth, adolescent, over 40, MSM (Saratoga County cited), prison releasee, young gay black men, Native American and transgender populations were singled out. It was noted that innovative models like the Damien Center (drop-in model) where peers provide important services must continue to be supported, and programs like this will be needed if intensive case management should no longer be available due to funding cuts.

### *Population-Specific Issues*

- **Adolescents:** Participants noted that particular attention needs to be paid to adolescents who were infected perinatally and have had to take medication their whole lives; they are prime candidates for non-adherence. There is a need for additional outreach and identification of adolescents. Similarly, there is great need to reach out to service providers to seek their assistance with testing and address the misperception that infections are not out there. One participant noted that the number of sexual partners for high school age individuals has increased and the age at first sexual experience has declined, suggesting an increased need for outreach and comprehensive sexuality education to this population. It was noted that perinatally infected adolescents have taken medications their whole lives and at this stage are expressing anger and fear about the disease. They become resistant to continue taking medications on schedule because it provides a reminder of their infection. Adolescents who are developmentally delayed need age-appropriate assistance with housing and social supports, even when medical status is stabilized. This is a challenge for care providers who cannot discharge these individuals from care and expect a level of self-sufficiency. Adolescents in foster care may require special services to assure their ability to access needed health and social services. Assistance in navigating documentation requirements is necessary. Youth empowerment programs are needed. It was noted that Arbor Hill Community Center supports a youth empowerment program that provides training for 15-21 year olds. It was recommended that this highly successful program be expanded to include information beyond HIV regarding challenges these youth face to assure best possible outcomes for this population.
- **Pediatrics:** Although fewer HIV-infected infants are born, the need for ongoing support for this population must not be dismissed.
- **Individuals over the age of 40:** County health departments see many individuals over the age of 40 who do not have a good understanding of HIV, its transmission and prevention. Seminars and trainings targeted to meet the needs of this population were recommended. Education and training is necessary for service providers that are focused on the needs of individuals as they age. Access to age-appropriate services, such as spiritual and emotional support, hospital, and pastoral care, was noted as a need. Mental health services must be targeted to meet the needs of this population. Long term care services must be sufficient in terms of quantity and experience in the care and treatment of long-term survivors.
- **Men Who Have Sex with Men (MSM):** A participant indicated that Saratoga County is seeing more MSM than in the past.

- **Transgender Individuals:** Additional transgender peers and peer advocates are needed who are familiar with and understanding of the unique needs of this population.
- **Incarcerated/Releasees:** Participants expressed concerns related to inmates and those recently released from correctional facilities. Some correctional facilities have contracted health care delivery to private vendors. This has resulted in less utilization of the Albany Medical Center DAC. Listening forum participants questioned whether the quality of care has suffered for inmates with HIV/AIDS. Care, treatment, prevention and supportive services for those newly released from prison were noted as significant unmet needs. Lack of adequate support in the areas of housing, substance abuse, mental health and employment contribute to a high recidivism rate. In Schenectady, a re-entry task force is being explored. Discharge planners in prison should ensure prisoners understand Medicaid restrictions and arrange for immediate access to services before release.

### *Rural Issues*

- **Transportation:** The availability of reliable transportation infra-structure in rural communities must be ensured because clinical care sites may be many miles away, across county borders and otherwise difficult to access, particularly when ill.
- **Testing:** Support for rapid testing is needed. Participants noted that counties currently absorb these costs but this may not continue as budgets become ever tighter. State support of local health department testing is necessary to ensure continued provision. Concerns were expressed regarding accessibility of confidential testing with appropriate follow up for care and treatment in Warren County. Testing and care referrals should be incorporated as part of contracts to ensure implementation.
- **Case Management:** Case managers play a critical role in rural counties. They may be the only person aware of an individual's HIV status and are the link between the client and services. It was noted that funding has remained level for years and no longer supports costs. Funding for case manager transportation costs (to meet with clients) is becoming ever more critical.
- **Physician Shortage:** The lack of physicians results in lengthy wait times, lack of ongoing care and compromised treatment adherence. Low reimbursement has resulted in few physicians providing care in rural communities. In Herkimer County, a small rural county, there are concerns that HIV has been "forgotten." Practitioners are not interested in caring for people with HIV.

### *Other Concerns*

- Participants viewed the character of their region as different from NYC. They indicated that physician familiarity and level of comfort with the care and treatment of persons with HIV infection is far greater in NYC than in the more rural areas of their region.
- Some participants emphasized the need for an upstate HIV Special Needs Plan (SNP).
- Participants suggested that community involvement in policy development must be broader than that currently provided through the New York AIDS Coalition (NYAC). Ryan White HIV Care Networks must be able to effectively respond to reauthorization issues.
- It was noted that AIRS users are not able to manipulate and pull data as needed. Participants advocated for streamlined, consistent standards and reporting requirements across the AIDS Institute.
- There was support for the movement to electronic medical records.
- Concerns were raised over the anticipated change in Article 27F of the Public Health Law, particularly over modification of provisions governing confidentiality and consent.
- Participants requested AIDS Institute involvement to help assure that consumer advisory boards are "real" in terms of community representation.

## Hudson Valley Region Listening Forums

The following issues were noted by participants in the Hudson Valley Region listening forums.

### *Prevention*

- **Harm Reduction:** Participants noted that increased emphasis on harm reduction programs is needed.
- **Education/Outreach:** Participants described a critical need to re-vitalize HIV/AIDS prevention education and outreach. Emphasis should focus on teaching prevention at an early age; enforcing NYS Education Department mandates on school-based education; consumer education; confidentiality training; and social marketing. It was noted that the teen street outreach program at Catskill Medical Center has been terminated. Participants identified migrant workers and day laborers as populations that need enhanced prevention education. It was noted that additional outreach is needed in Sullivan County.

### *Health Care*

- **Health Care Provider/Specialist Shortage:** A shortage of providers was identified in the areas of dental, medical, counseling, substance abuse, and mental health in the Hudson Valley Region. There is also a region-wide shortage of specialty providers in the areas of ophthalmology, urology, psychiatry, orthopedics, and pain management. Ulster County noted a lack of access to pain management, ophthalmology, urology, and psychiatry. Sullivan County, in addition to an overall shortage of specialists, reports a lack of respiratory therapists that accept Medicaid. Westchester County indicates difficulty in securing diagnostic testing, such as liver biopsy and ultrasound, on a local level. Some health care providers are facing difficulties with physicians no longer accepting Medicaid. It was noted that pain management providers do not accept Medicaid, ADAP, or Medicare. Westchester providers routinely refer to NYC for pain management which requires inter-county Medicaid transportation.
- **Acute Care:** DACs play a critical role in the care of PLWHA in this region. DACs provide good care and wrap-around services and are the cornerstone of HIV specialty care and treatment.
- **Substance abuse/addiction treatment:** Participants noted a shortage of substance use services in the region. In Dutchess County, nearly one-half of HIV cases are IDU. It was noted that Ulster County has a shortage of providers and a long waiting list for MMTP services. As a result, clients have to cross county boundaries to access services, which is difficult due to Medicaid transportation limitations. It was noted that an unmet need for buprenorphine in Westchester County results in referrals to the Bronx, and Westchester County Medical Center has no physicians who prescribe it.
- **Mental Health:** Mental health services in the region are generally limited. Long waiting periods to see mental health counselors and psychiatrists lead to lapses in treatment and medication that compromise patient care. It was noted that the Ulster County Mental Health Department is the only psychiatric provider other than the emergency department. There is a three-month wait to see a counselor and another three months to see a psychiatrist. Individuals are often discharged from inpatient psychiatric stays with 30 days of medication and have no way to re-fill prescriptions. It was noted that Catskill Regional Medical Center recently lost their psychiatrist, and there are no local prescribers that accept Medicaid, ADAP or Medicare. There is a need for adherence services for the mentally ill.
- **Dental Care:** The lack of available dental care was universally cited. There is a lack of dentists in the region who accept Medicaid and ADAP Plus. Ulster County is facing a particularly severe provider shortage for persons with HIV. Participants noted that dental services at Westchester County Medical Center are being reduced. More geographically accessible and culturally competent dental services for PLWHA are needed.
- **Integration of Care:** With increased life spans, PLWHA are experiencing more generalized medical problems associated with aging. Therefore, the need for coordination and integration of HIV/AIDS care with other care is becoming even more important. Increased integration is needed among primary care,

STD, Hepatitis C, substance abuse, and mental health services. It was noted that Community Health Centers are failing, so a comprehensive, integrative approach to care is more challenging. A “one-stop shopping” model with co-located services, similar to the VA system, was suggested as a model to promote this coordination of care.

- **Quality Monitoring:** Flat or reduced reimbursement may result in reduced quality of clinical and non-clinical services. Under the Ryan White, funding for items that are not considered direct clinical care, such as quality monitoring and provision of supportive wrap-around services, may suffer. As a result, AIDS Institute quality monitoring results may indicate a decline. It was suggested that quality standards continue to be enforced and assurances be made that funding will continue to support quality services. Participants suggested that this is especially important in light of managed care, when payments to providers are no longer under the direct control of the AIDS Institute.
- **Long Term Care:** Specialized services are needed for nursing home residents with HIV/AIDS, particularly younger residents.

### *Health Care Financing and Health Coverage*

- **Reimbursement Issues:** Issues related to the reimbursement rules of ADAP Plus and Medicaid were a major concern during the forum. It was recommended that the scope of services paid for by ADAP Plus should be expanded. It does not pay for inpatient and emergency services or for non-HIV related services such as MRIs, x-rays, biopsies, and CAT scans. For example, a patient with chronic hepatitis C with ADAP cannot get an ultrasound or biopsy. It was recommended that the scope of coverage be expanded to meet the needs of individuals living with HIV as they age and develop multiple co-morbidities that require treatment for illnesses not currently covered by the program. ADAP Plus coverage should facilitate securing wrap-around services. Many county social services departments will not authorize Medicaid payment for out-of-county services; Ulster County was referenced. Many providers do not accept Medicaid or ADAP. More financial incentive is needed for physicians. Medicaid restrictions on transportation also present a barrier to care.
- **DAC Reimbursement:** Participants were apprehensive about the movement to APG reimbursement formulas and proposed mandated Medicaid managed care. It is anticipated that these changes will adversely affect DAC reimbursement. Participants expressed concern that in light of this, hospitals may elect to drop their DACs or not maintain the level and quality of staff necessary to provide needed care. Participants indicated that the Catskill Regional Medical Center clinic transitioned to Hudson River Health Care, and concern was expressed that Westchester County Medical Center will follow suit and terminate its AIDS program. Participants asked the AIDS Institute to advocate for the retention of DACs with hospital administrations.
- **Coverage Issues:** Half of patients seen are charity care (no Medicaid, no ADAP). It was noted that the ADAP Plus Insurance Continuation (APIC) Program’s requirement for payment of the first premium presents a barrier for some clients, especially for seasonal farm workers and the undocumented. Many patients cannot afford required health insurance co-pay fees.
- **Provider Education:** More information on coverage is needed as rules and guidelines are not always clear. An ADAP guidebook was requested. Information on the Medicaid program in each county in the region was also requested.

### *Supportive Services*

- **Transportation:** Transportation remains an urgent, critical need in this region. Participants noted that most counties do not have needed specialists; therefore, patients must travel to NYC for care. Medicaid restricts the use of medical transport and will not provide taxi service to appointments outside the consumer’s county of residence. This is a barrier that can impede a patient from receiving necessary care. Another concern is the lack and/or restricted availability of intra-county transportation in rural areas.

Further, a physician certification of need is required to obtain Medicaid-covered transportation. The specific examples noted by participants included the lack of transportation in Sullivan County, Rockland County's policy of no pick-ups after 3:30 or 4:00 p.m., and transportation limitations in Orange County. The need for better emergency transportation was also raised.

- **Housing:** There are shortages of affordable housing throughout the region. A critical shortage was noted in Newburgh, and Dutchess and Sullivan Counties were also specifically mentioned. The availability of housing is particularly difficult for the working poor (those who earn \$30,000 to \$40,000 per year). Rental assistance is also difficult to secure. Crisis ("safe house") accommodations for the homeless and immediate assistance for domestic violence victims are needed. Homelessness is a barrier to treatment adherence, and an address is needed to file applications for services. It was noted that the stigma of HIV/AIDS, which some in the group consider worse now than in the 1990s, may be a deterrent to PLWHA actively seeking housing. There is an additional barrier facing HIV+ prison releasees. Section 8 denies housing to people with criminal histories. A suggestion was made to increase temporary housing by using FEMA trailers.
- **Legal Support:** There is a critical need for increased legal services for PLWHA in this region. General legal services are needed that would allow individuals to focus on health care needs. In addition, services are needed specific to income maintenance, family law issues, and end-of-life issues.
- **Case Management:** Participants cited areas for improvement in case management and stated that effective case management is essential to accessing needed care. It was noted that limited funding has resulted in the inability to hire and retain good staff leading to frequent turnover that becomes a barrier to continuity of care. Participants indicated that better salaries are needed for case managers, and funding for case management must continue regardless of other reimbursement reforms and budget restrictions. In an effort to limit duplication, individuals have been forced to use a single agency for case management when they might be better served by using multiple agencies. Participants indicated that coordination between COBRA and day care/home care is difficult for some clients and that clients should not have to choose between COBRA and day care or between COBRA and home care.
- **Support Services:** The movement of Ryan White to a medically centered model was supported by some participants because of the aging HIV/AIDS population. However, others warned against pushing all programs toward a medical model. Participants advocated for additional support groups and enhanced support services and counseling particularly for day laborers, migrant and seasonal farm workers, the children of PLWHA, and the undocumented. The point was made that consumers need somewhere to go to speak and interact with peers. The importance of good counseling was noted as was the frequent turnover of counselors. More support is needed for staff working in the field.

### *Population-Specific Issues*

- **Day laborers/Migrant workers/Seasonal farm workers:** It was noted that there are seven different communities represented in Westchester, each with their own language; many are undocumented. Participants identified a lack of health coverage and the need for enhanced cultural and linguistically appropriate outreach, medical and support services, and prevention education as major issues.

### *Other Concerns*

- It was noted that Dutchess County is scheduled to be phased out as a Ryan White Part A transitional grant area (TGA). If eliminated from the program, the loss will be \$1 million. Concern was expressed about how this will impact the HIV/AIDS population.
- Data on newly diagnosed cases was requested. AIRS was noted as difficult to use and not well suited to provider needs. HIVQUAL data was requested too late in the year so it was not useful for year-to-year comparisons. Participants noted that the data on the NYS DOH website is extremely outdated.

- Food stamps provide critical support. Resources to support emergency financial assistance for basic subsistence must be increased. One participant stated that food stamps were reduced when rental assistance was obtained, leaving the individual without enough money for expenses and food.
- Some participants expressed strong sentiment that HIV/AIDS is an infectious disease causing deaths; it should not be labeled a chronic disease.

## Long Island Listening Forums

The following issues were noted by participants in the Long Island Region listening forums.

### *Prevention*

- **Harm Reduction:** Syringe exchange programs (SEPs) have been successful in reducing transmission of infections. It was suggested that at least one of these programs should be available in the region. Participants noted that some pharmacies participating in the syringe access program (ESAP) continue to create barriers to access to syringes. Pharmacists need additional education.
- **Counseling and Testing:** There is a need for additional access to voluntary testing and counseling. Routine testing and linkages to care in a variety of settings are needed. Both medical and non-medical service providers must reinforce the need for testing. The lack of testing sites in Suffolk County was particularly cited. Additional anonymous testing sites and testing sites that focus on adolescents are needed. It was suggested that student-led testing days be held at SUNY Stony Brook. Participants noted that there is a general lack of hospital support of HIV services, including testing. The obstacles to emergency department testing cited by hospitals include coverage for the uninsured, the cost of test kits, and the resultant increase in workload. It was suggested that rapid testing is far superior in encouraging persons to test, but the lack of funds to purchase test kits and a short shelf life make this method of testing difficult to provide. (Note: Shelf-life was recently increased for newly manufactured product.) Payment for counseling and testing services for the uninsured is a concern.
- **Education/Outreach:** There needs to be a re-invigoration of prevention education and outreach in the region. Participants in the listening forums suggested NYS should employ active use of the media for consumer outreach and education including social marketing and public service announcements (PSAs). Educational and outreach efforts must also be stepped up in schools, especially in high schools. It was noted that school-based HIV education is lacking and educational mandates are not being met. There should be an HIV advisory committee in every school district, and it should be active and involved. Prevention and reduction of risky behaviors, particularly directed at increased condom use, are areas that need promotion in all age groups and all special populations. Adolescents and incarcerated youths were two specifically identified target groups. These groups could also benefit from education directed at how to resist gang pressures for risk taking. Consumer advisory committees and local health departments (LHDs) must take a lead role in community education. State/county/local coordination must be promoted to ensure provision of the full complement of prevention and care services. It was noted that budgetary pressures have reduced the capacity of the LHDs to provide needed education.
- **Coordination:** Coordination of HIV/STD/teen pregnancy prevention was suggested.

### *Health Care*

- **Health Care Provider/Specialist Shortage:** A shortage of specialists in the region was noted with gastroenterologists and physicians specializing in HIV care specifically identified. There is need for more availability of eye care and dental services. Transportation restrictions further aggravate these shortages.
- **Acute Care:** Resources are needed throughout the DAC, including grant funding, to support an array of services.
- **Mental Health:** The shortage in mental health services, including psychiatric care, was raised. There are shortages in services for both adults and children. A participant indicated that it can take from six months to one year to get a psychiatric evaluation. In addition to addressing the psychological needs of clients, a strong mental health component of care is critical to HIV treatment adherence, retention in care and positive health outcomes. There is concern over the level of mental health coverage provided by managed care.

- **Integration of Care:** A large number of PLWHA are affected by co-morbidities. One example cited was the high level of hepatitis C/HIV co-infections in Suffolk County. Participants indicated that there were few providers willing/able to provide the comprehensive care these patients require. It was recommended that HIV specialists broaden their area of expertise to include hepatitis C. The effective collaboration of HIV, STD, hepatitis C, mental health, and substance abuse service providers is necessary to properly care for complex medical cases. Comprehensive treatment models have been found to be effective, including same day services at a single site. Better communication between health care facilities and CBOs was also recommended to assist in coordination of care and services. Participants indicated that hospitals were reluctant to promote HIV/STD services.

### ***Health Care Financing and Health Coverage***

- **Coverage Issues:** Concern was expressed about lack of health care coverage for immigrants. There was praise from participants for ADAP; however, it was noted that it does not cover all medications that are needed by patients. Participants indicated that the limitations of ADAP Plus and Medicaid coverage are a barrier to proper dental care. Specific mention was made of root canal procedures. One participant noted that a patient had a root canal started and was then told it wasn't covered, so the root canal can't be finished. Since Long Island residents are not in the SNP service area, there is apprehension over the move to mandatory managed care for persons living with HIV. There are concerns about managed care, including its restriction on mental health services and whether there will be enough primary care physicians enrolled to provide care for people with special needs.
- **DAC Reimbursement:** Participants expressed concern that the loss of tiered billing, the move to APGs and the elimination of the HIV exemption for mandatory Medicaid managed care could result in the loss of the DAC system and its focus on comprehensive, coordinated care. Hospitals have put resources into the DAC because of enhanced reimbursement. The opinion was shared that without enhanced reimbursement, the DAC model cannot be sustained.
- **Provider Education:** It was noted that training for case managers and substance abuse counselors is needed. Additional training in cultural competency for care givers and service providers is also needed.

### ***Supportive Services***

- **Transportation:** Additional transportation resources and a more enlightened reimbursement policy regarding transportation are required. Participants voiced concern over the lack of transportation and county Medicaid restrictions, particularly in Suffolk County, including advanced notice that is not always possible, limited trips depending on the remaining budget, cross-county restrictions, and the requirement that round-trip transportation be of same mode, which is not always practical. These transportation issues create barriers to securing specialty care in particular. An example was given of a patient diagnosed with Cytomegalovirus (CMV) who was not able to secure transportation to an ophthalmologist. The need to document the use of metro cards for every trip is considered a barrier to providing service. A need for enhanced emergency transportation was raised.
- **Housing:** A lack of affordable, safe, clean and stable housing in the Nassau/Suffolk Region is a pressing problem for PLWHA and their families. The tenuous nature of housing for many HIV positive individuals disrupts their ability to maintain adequate connections to medical, mental health, substance abuse and social services providers and to adhere to medication regimens. The utilization of emergency housing often breaks up families. It was noted that foreclosures have a far greater impact on tenants than homeowners.
- **Legal Support:** Part A restrictions have limited the availability of legal services to PLWHA, particularly to assist persons with housing in the face of foreclosures. It was noted that there is a far greater impact of foreclosure on tenants than landlords or home owners, in terms of numbers of people affected.

- **Case Management:** Participants stated that case management services are insufficient, not well coordinated, and do not provide effective follow-through. It was noted that case management providers have experienced staff reductions that have limited the ability of providers to facilitate coordinated care with other agencies, resulting in less effective access to care and treatment. Improved communication with service providers was recommended, including via regular meetings with hospitals and CBOs.
- **Support Services:** Participants indicate that the movement of Ryan White to a medically centered model is adversely affecting support services essential to PLWHA. Participants advocated for cultural, linguistic and age appropriate support services focusing on adolescents/youths, immigrants, day laborers, Latinos, the transgendered, persons over 50, the incarcerated and the homebound. Support/peer groups, day programs, group homes and legal support are among the services most needed. The importance of treatment adherence and retention in care need to be reinforced. Nutrition assistance is also considered an important need. It was suggested that food be served at group meetings/programs to assist attendees in meeting nutritional requirements. Participants noted that the lack of support services, specifically housing, food, and transportation, all translate into lack of access to care. Listening forum participants indicated that reduced funding for health departments has resulted in service cuts.

### *Population-Specific Issues*

- **Adolescents/Youth:** Participants indicated that adolescents are a vulnerable population in this region and noted that school based-education requirements are not enforced and high schools provide very little support. Adolescents need age-appropriate education and support services encompassing pregnancy prevention; treatment adherence; risk reduction including condom use, safe sex behaviors, and resisting gang pressures; relationship education; and the transition from adolescent to adult care settings. Adolescents who have not disclosed find it difficult to access care, so support is also needed in initiation of and retention in care. Support must continue for youth/adolescents who were perinatally infected. Specific initiatives directed at this age demographic were suggested including ensuring a broader availability of condoms; coordinating HIV, STD and teen pregnancy prevention services; encouraging youth boards that promote positive youth development models; and establishing more group homes to provide teens a safe haven. It was noted that there is an increasing number of children needing services originating from the immigrant community and single-parent households. Services are needed for incarcerated youth.
- **Immigrant/Day Labor Population:** Participants indicated that Long Island has a large South and Central America population who face significant barriers to care and treatment including lack of insurance, undocumented status, issues of disclosure, and language barriers. Many speak native languages (not Spanish). Comprehensive treatment models have been found to be most effective with this population, including same-day services at a single site. Culturally and linguistically competent outreach, support and services geared for both adults and children must be available and accessible to this population.
- **The Latino Community:** Participants indicated that this population experiences difficulty in accessing services because of language barriers and the limited number of service providers who focus on their issues. Cultural influences also present powerful barriers to care. Culturally and linguistically competent outreach and support services must be available and accessible to this population.
- **Incarcerated:** Concern was expressed over the quality of care provided to prisoners with HIV/AIDS. Participants indicated that medications may not be provided on time and people may receive the wrong medication. Youth in correctional facilities need prevention education.
- **Persons over 50:** Participants indicated that little attention and few services are directed to this population despite the fact that with advancing age, there are increased morbidity and mortality concerns. Harm reduction services are also needed.
- **Transgendered Individuals:** There is a need for services targeted to this population.
- **The Homebound:** Additional services are needed for homebound individuals.

## *Other Concerns*

- Required services must be maintained despite budget cuts.
- Participants expressed concerns related to data. Some noted that AIRS is not user-friendly. Participants indicated that the HIV/AIDS data available on the NYS DOH webpage is outdated and, as such, is not helpful. HIVQUAL indicators should be more useful to facilities and less burdensome to report.
- Lack of employment leads to financial difficulty, but a fear of losing the assistance gained because of that difficulty creates a barrier to finding and keeping employment.
- AIDS is not a chronic, manageable disease.
- Participants indicated that the stigma of HIV/AIDS and homophobia still exist and are barriers to disclosure and securing needed care and services. These issues must continue to be addressed.

## New York City Listening Forums

The following issues were noted by participants in the NYC listening forums.

### *Prevention*

- **Harm Reduction:** It was noted that a syringe exchange program (SEP) is needed on Staten Island. Participants report difficulties with pharmacies participating in the syringe access program (ESAP). Additional education is needed to promote better cooperation.
- **Counseling and Testing:** There is a need for additional HIV counseling and testing services in NYC, and on Staten Island in particular. Participants suggested that testing should be incorporated into general medical care with the offer of a test mandatory. If/when a written informed consent is secured, access to rapid testing should be facilitated. It was recommended that the HIV test be among a battery of tests given coincidentally, including tests for HCV, STDs, and pregnancy. Testing should also be available at other health care venues. For example, it was noted that testing of clients while at a dental appointment has proven effective and should be employed more broadly. Participants indicated that Daytop Village has implemented expanded testing by nurses with peer counselors providing case management, and it appears to be an effective model. Strategies also must be implemented to draw more people to testing early on. One suggestion was to encourage social networking around testing and bring members of the social network in for testing. Use of chat lines to engage people in testing may also be successful. Testing must be available at convenient times, for example at night and on weekends. Late testing may be the result of a lack of trust among certain populations, particularly transgendered individuals. Targeted interventions should be implemented for these populations. HIV testing for active substance users is critical and may require provider education to implement effectively. Additional funding for test kits is required. Participants indicated that while testing itself may be simple and straightforward, the paperwork associated with it is onerous.
- **Education/Outreach:** Participants indicated that prevention efforts must be louder and stronger in order to be successful. Effective Community Advisory Boards that involve PLHWA in every step of planning are needed. Outreach and education strategies must be sensitive to the culture, language, and preferred learning methods (e.g. visual, written, word of mouth) of the target population. These strategies should utilize social events, such as parades, festivals and youth gatherings, to increase awareness of prevention and the location of testing, treatment and support services. Media and social marketing campaigns were also suggested. Young men and MSM were specifically mentioned as targets for these campaigns. Consumers need to hear prevention messages from consumers/peers. HIV Stops with Us and other campaigns should be more visible. Participants stressed the need to reach young people before they are infected. The need for advocacy training was also identified. It was recommended that the faith community be actively engaged. Improved interaction between providers and the faith community should be cultivated. Outreach efforts should not marginalize religious leaders. An effective method for reaching the Black community is through its churches. It was noted that the influence of Voodoo beliefs must be recognized, and outreach and education must be delivered in an appropriate manner. Participants stated that it is critically important to reach out to Cuban, Haitian and African communities, and Muslim communities must be engaged independent of Jewish or Christian communities. Educational initiatives must be directed at the danger of “hooking-up” through Internet sites that has led to an increase in STDs. Along with prevention, education/outreach must focus on retention in care so people do not fall through the cracks. Resource directories and mentors would assist with retention in care. The availability and location of services need to be better publicized. One participant indicated that it is difficult to find out where to get services in Queens.
- **Schools:** It was noted that the NYS Education Department and the NYC Board of Education must be key players in providing youth education. Effective AIDS education must be delivered in schools. Participants identified the Hispanic and immigrant populations as having a critical need for such education. Additional vocational education programs are needed.

- **STD Services:** Participant noted that many STD clinics have closed in East and Central Harlem.

## *Health Care*

- **Health Care Provider Shortage/Burnout:** Participants indicated that there is an overall lack of HIV specialists. People must wait three to four hours to see a physician, so they leave, and many do not return for care. Because HIV providers are caring for greater numbers of infected persons, including many with difficult-to-manage co-morbidities such as mental illness and substance abuse, they are experiencing increased burnout. This further aggravates the situation. Providers are not afforded sufficient time with patients to deliver care, treatment and adherence messages.
- **Hepatitis C:** It is difficult to make appointments for treatment of hepatitis C. Even in urgent situations, sometimes you can't get an appointment for three months. Integration of hepatitis C services within MMTPs would facilitate coordinated care. Outreach and education continue to be critical to address misperceptions.
- **Mental Health and Substance Use:** Participants indicated that there is an overwhelming need for mental health services, psychiatrists, and specialized long-term psychiatric facilities. Participants also recommended lifting the moratorium on Article 31 licensure. Participants noted that there has been a huge increase in the number of HIV/AIDS patients with mental health diagnoses. Early identification of HIV and mental illness is critical for long-term success. Participants noted that 40 to 60 percent of HIV-positive patients require mental health referrals, and a large percentage of the population is on anti-psychotic medication. Participants also stated that a large percentage of substance-using patients need psychiatric care. Cognitive dysfunction and substance abuse compromise the overall effectiveness of care and services. These issues must be identified in clients, and mental health and substance abuse support must be made available. Assistance is needed from mental health professionals in program development and treatment.
- **Home Care/Nursing Home Care:** Participants indicated that the cap on long term home health care (LTHHC) services is inappropriate given extensive service needs of persons living with HIV and numerous other co-morbidities. LTHHC/COBRA coordination is useful and should be continued to assure ongoing access to care for those in greatest need. Participants noted that a client can't be in the LTHHC Program and managed care at the same time. It was recommended that novel approaches to home-based care be explored that would assist those clients who are most difficult to engage and who may otherwise fail to thrive. A concern was voiced that AIDS nursing homes cannot adequately treat mentally ill patients. Assistance is needed for nursing homes that care for multiply diagnosed HIV+ residents -- Rivington House, for example. A participant noted that 70 percent of Rivington House's residents are triply diagnosed, and 60 percent are infected with hepatitis A. There is an insufficient number of mental health providers for the case-mix, and the cost of medical and behavioral health is significant. Participants indicated that pharmacy costs are prohibitive resulting in some patients being turned away, and medications for chronic illness are not reimbursed fairly.
- **Provider Education:** The provider community needs enhanced training on customer service as well as cultural sensitivity and competence focused on the populations they serve. Training for health care providers in dealing with substance users was also suggested. Additional training is needed for physicians in the care of persons over 50.
- **Dental Services:** Additional dental services are needed.

## *Health Care Financing and Health Coverage*

- **ADAP/ADAP Plus:** Questions and concerns arose regarding services covered by ADAP and ADAP Plus and why coverage is not extended to non-HIV care needs. ADAP Plus was described as more difficult in terms of securing wrap-around services and specialty care, and as limited for patients who present with co-morbidities such as cancer. A lack of ADAP Plus-participating radiologists was noted. It was noted

that there is little physician incentive to participate in ADAP Plus, and care needs to be incentivized. ADAP Plus coverage for only outpatient services is limiting. Questions were raised regarding dual coverage and spend-down. ADAP income eligibility requirements need to be flexible. Some people that exceed income limits still need assistance in getting medications. Participants commented that the APIC requirement for participants to make the first insurance payment is difficult for many (particularly the undocumented), as they do not have money up front to pay a premium.

- **Managed Care:** Participants expressed broad-ranging concerns over the movement to mandatory managed care. Consumers questioned the rationale for the decision to end the HIV exemption. Participants stated that the exemption was originally based on medical and care concerns and asked what has changed. The impact of mandatory managed care on PLWHA on Staten Island is of particular concern, since there are no Special Needs Plans (SNPs) available to them. The success of managed care will be a function of the provider's ability to accurately and effectively guide patients in terms of enrollment. Managed Care Organizations (MCOs) need to focus on outreach, education and distribution of enrollment packets to individuals and provide enough time for individuals to make an intelligent enrollment decision. Many believe that 90 days is not an adequate timeframe. The availability of case managers to help individuals navigate new care systems is critically important. Additional funding for case management is needed. Concerns were voiced regarding ongoing quality of care delivered under managed care. Standards of care must be enforced at mainstream plans. The opinion was shared that managed care has very strict rules and limitations on mental health and substance abuse treatment. Concerns were raised that persons with multiple co-morbidities will not have access to highly specialized services. Continuity of care is an issue for SSI recipients. Education at the consumer level is needed including identification of questions that consumers might ask providers.
- **Other Issues:** Participants voiced other concerns related to reimbursement and health care coverage. The movement to APGs was questioned, both in terms of reimbursement and program integrity. Medicare Part D prior authorizations were termed a "nightmare." Lack of health care coverage, especially for immigrants, the undocumented, and seniors, is a barrier to care. There is a lack of physicians in Staten Island that accept Medicaid.

## *Supportive Services*

- **Transportation:** Participants indicated that there is no transportation available for non-emergency situations, and ambulances will only take people to the emergency room. Transportation is needed in situations where people need to see the doctor but are too ill to walk or take public transportation.
- **HASA/Housing:** There is a need for supportive housing for clients that are not substance abusers. The rent cap that exists for PLWHA is important and should be retained. The current requirement that people in housing can only keep 30 percent of their income was criticized. Participants voiced concern over the fact that HASA rejects the eligibility of people based on their CD4 count regardless of other clinical indicators. The current benefit system establishes contradictory incentives. Clients begin with a full range of services, and when they return to work, services are withdrawn. This creates a disincentive to go back to work.
- **Legal Support:** It was noted that some clients over-rely on case managers for advocacy that is more appropriately within the purview of legal services. Legal advocacy services are critical to ensure effective medical care and support services and to keep people housed. Dedicated legal service providers are essential. A participant indicated that Families in Transition funding is the only money for legal services. Participants indicated that the availability of legal services on-site at medical providers would be of great assistance.
- **Case Management:** Case managers serve as advocates for clients and help them navigate the service delivery system. The continued availability of funds to assure access to case management is critical, regardless of other reimbursement reforms and budget restrictions. Limited funding results in an inability to hire and maintain qualified staff, leading to frequent turnover and discontinuity of care. It was noted that case manager caseloads are extremely high. Grant-funded case management often acts as a bridge to

transition individuals back into care and must continue to be supported. Participants believe that the prohibition on dual enrollment in COBRA and LTHHC does a disservice to the client. It was noted that some clients over-rely on case managers to advocate in areas where legal counsel is needed.

- **Support Services:** Participants indicated that PLWHA need more than medical services. The movement of Ryan White to a medically centered model is adversely affecting support services essential to PLWHA. Participants advocated for support services that make it easy for people to actually live with HIV/AIDS (e.g., work, school, etc.). Services that deal with the family structure and address family needs were also advocated including support and education focusing on domestic violence. Services must support retention in care and treatment adherence. Participants indicated reminding clients of appointments helps with retention, as do peer groups and peer mentoring. It was suggested that the level of peer support would be enhanced if peer stipends were not considered as income by SSI/SSD. Clients need support with issues relating to confidentiality and disclosure. It was stated that many live in fear that the community will learn their status, and many do not wish their family to know. Services should be available outside their borough so they can maintain anonymity. Specific support needs were identified for the incarcerated and recently released, adolescents, communities of color, Native Americans, Asian/Pacific Islanders, MSM, persons over 40/50, heterosexuals with HIV/AIDS, immigrants, the transient population, persons with learning disabilities, the deaf, PLWHA on Staten Island, and the multiply diagnosed. There is also a need for home engagement of the homebound and persons otherwise unable to participate in support services. There is a need to reach the “failure to thrive” individuals who are not in care and do not or cannot take their medications. Participants stressed that support services must be culturally, linguistically and age appropriate. They must also be available on weekends and evenings so that working people have the opportunity to participate.
- **Food and Nutrition:** Participants identified food and nutrition services as critically important and took issue with current rules that limit food and nutritional services to medical nutrition therapy only. There should be more latitude. Participants commented that medical nutrition therapy without the provision of food is meaningless. Food helps people manage disease, stay on meds, and stay in care.
- **Treatment Adherence:** A non-physician capacity to assure treatment adherence is critical. Pharmacies should partner with physicians in assuring treatment adherence. It was suggested that auto refills and prompt dispensing assist with adherence but may also result in waste when treatment regimens are altered. Substance use and mental health needs complicate HIV treatment adherence.

### *Coordination/Integration Issues*

- **Coordination/Integration of Care and Services:** It was suggested that HIV be integrated with general medical care and STD, hepatitis C, mental health, and substance abuse services. This would facilitate testing, diagnosis and comprehensive treatment of co-morbid HIV patients. Efforts should be made to co-locate these services to maximize the convenience to patients and to ensure compliance with patient referrals. Data indicate that the compliance rate for off-site services is only 20 percent to 25 percent. Patient navigators help with coordination issues for those who are referred to multiple sites for care. Participants indicated that while HIV is making attempts to better coordinate and co-locate, other services (e.g., mental health) are resisting.
- **Coordination Among Organizations/Agencies:** It was noted that coordination and sharing of information among agencies and organizations is of paramount importance. Coordination between State and City agencies is key, especially when providers are confronted with multiple, new funding streams. Competition and the lack of coordination and networking among providers result in providers trying to “hold on to clients” rather than help them to become self-sufficient/independent. The following recommendations were made: information sharing should be enhanced between the AIDS Institute and the NYC HIV Prevention Planning Group; minority agency development would be facilitated through enhanced collaboration/coordination between agencies; smaller agencies should share resources and should collaborate around fiduciary responsibility; dissemination of information must be improved and be more creative. Information on State and federal fiscal issues should be shared with service providers and

planners, and a city-wide resource directory should be developed. In the best interests of clients and given the current fiscal situation, services and care must be coordinated, integrated where possible and efficient. Silos must be broken down.

- **Planning Initiative:** It was recommended that the AIDS Institute convene a meeting of all providers (mental health, psychiatric, substance use, etc.) to discuss service needs and ask for a plan to effectively and efficiently meet patient needs. This would provide the basis for shaping future policy and identify the resources that would be needed.

## *Population-Specific Issues*

- **Incarcerated/Releasees:** A participant noted that persons discharged from Rikers Island with alcoholism and mental health needs that are not met in the community often end up back in jail or in prison.
- **Communities of Color and Minority Health:** It was indicated that in the African American community, mental health is a significant risk factor. Sexual identity is a public health issue in the African American community because most African American males will identify only as heterosexual because their community does not accept homosexuals. Fear of disclosure can significantly delay testing and initiation of care and services. There needs to be a clearer understanding of African American identity issues. Research is needed to better understand and address the disproportionate impact of HIV/AIDS on communities of color. There must be services for young Hispanic men. Strategies must be developed to draw women of color into care and to accentuate health-seeking behaviors in the minority community.
- **Adolescents:** A participant noted that adolescents infecting each other is a significant issue. Enhanced education is needed to reduce transmission. The stigma of HIV/AIDS is pervasive in this population. Infected children who have now grown into adolescence experience unique challenges and difficulties and need support. Many of those who were perinatally infected have a psychiatric disorder. Mental health services are important to those adolescents. The timing of transitioning adolescents to the adult care model should be highly flexible and individualized. Chat lines can be used to promote testing; however, this population must be advised of the danger of “hooking-up” through chat-lines and other Internet sites. It was noted that budget cuts have reduced services for this population.
- **Men Who Have Sex with Men:** Participants indicated that this population may be underreported. A sustained and focused social marketing campaign stressing the need for testing and prevention is required. Additional targeted services are needed.
- **Native Americans and Asians/Pacific Islanders:** Participants stated that these populations are generally underserved and require targeted care and services.
- **Deaf Population:** This population has a great need for services in NYC.
- **Persons with Learning Disabilities:** Services are needed for this population.
- **People Over 40/50:** Participants indicated that AIDS is perceived as a young person’s disease, and often this generation experiences a lack of respect when seeking testing or care. However, this population needs targeted services and prevention strategies. As persons age and are diagnosed with multiple co-morbidities, care and treatment becomes more difficult especially for those who lack health insurance. Individuals without insurance often forgo preventive care (e.g., breast cancer screening). This can lead to long-term health care issues. Women over 50 need specialized supportive services and resources, and they need their own environment. Caregivers for this population must be age appropriate and educated on how to effectively deal with this population.
- **Heterosexuals:** It was indicated that many existing providers are known as gay-friendly and are not considered a “safe space” for older heterosexual women. A participant indicated that many HIV-positive individuals seen at Alianza are heterosexual and over 40.
- **Immigrants:** It was suggested that the AIDS Institute consult and collaborate with consulates to better address immigrant needs (e.g., the Mexican consulate has programs for PLWHA). Greater outreach and education to immigrant communities is needed, and the full range of health and support services must be made available to this population. Language concerns continue to create barriers to care and must be

taken more seriously. The undocumented are reticent to access care due to fear of discovery. It was noted that transmission of HIV/AIDS from/to persons in the country of origin continues to be a significant issue. Participants suggested that Washington Heights is a particular area of need of services. Care for Caribbean immigrants is limited. Services unified at a central location would help this population. Immigrant stigma and discrimination is pervasive and must be addressed.

- **The Multiply Diagnosed:** There are limited psychiatrists to refer patients to. Without psychiatric treatment, medical care is often difficult to deliver. A large percentage of substance users have psychiatric disorders. These individuals carry multiple stigmas, lack adequate health coverage, and often do not understand what services they require.
- **Staten Island Residents:** There are very limited services available on Staten Island. It is not covered by a SNP and does not have a DAC. There is only one physician that accepts Medicaid patients. Participants stated that late diagnosis is common, as many individuals are older, married and have children. In addition to a lack of health care resources, the most pressing needs on Staten Island were identified as harm reduction and syringe access sites, enhanced information and outreach activities, and additional testing sites.

### *Other Concerns*

- **Service Provision During Difficult Fiscal Times:** Participants indicated that budget cuts at the State, federal and local levels, coupled with decreased private fund-raising in these tough economic times, are impacting service provision and the lives of clients. Efficiencies must be maximized, and organizational silos must be broken down and services integrated. It was suggested that funding reductions be strategic, based on performance and service delivery rather than across-the-board reductions. Allocation of scarce resources must be based on sound policy, priorities, and future direction. The current procurement process is time consuming and costly; it should be re-examined. It was suggested that outreach should be directed to the HIV Care Networks for suggestions regarding innovative and effective care and treatment models. A meeting of all service providers should be convened to plan effectively to meet patient needs and shape future policy.
- **Data and Reporting Issues:** Participants voiced a number of concerns about AIRS. It was noted that documenting counseling and testing in AIRS is very slow (10 to 12 minutes to enter an encounter); use of AIRS on more than one computer can drastically slow down data entry; there are problems extracting data from AIRS; and dental services can only be reported as a referral even if they are done onsite. There was support for electronic medical records (EMRs) in small agencies as a method to facilitate coordination among agencies and reduce redundant reporting to funders and control agencies. The point was made that current reporting is fragmented, redundant, and unnecessarily time-consuming, and it does not facilitate sound planning. E-Clinical Works will not allow for the incorporation of mental health information and does not communicate well with AIRS. The point was made that quality management and quality reporting is a burden. It should be consolidated and streamlined so providers can deliver services rather than drowning in paperwork.
- **AIDS Exceptionalism:** The talk of an end to AIDS exceptionalism is of great concern to those who believe that all medical care should mimic the comprehensive continuum of coordinated care and services provided to PLWHA. The need to preserve standards and quality in a changing environment was emphasized.
- **Stigma and Discrimination:** It was noted that stigma is more intense today than in the 90s. A well funded marketing campaign will help to address stigma and persuade behavior change. HIV Stops with Us and other campaigns should be more visible. Additional public service announcements were requested.
- **Pharmacies:** Participants indicated that some pharmacies may short-change people on their pills.

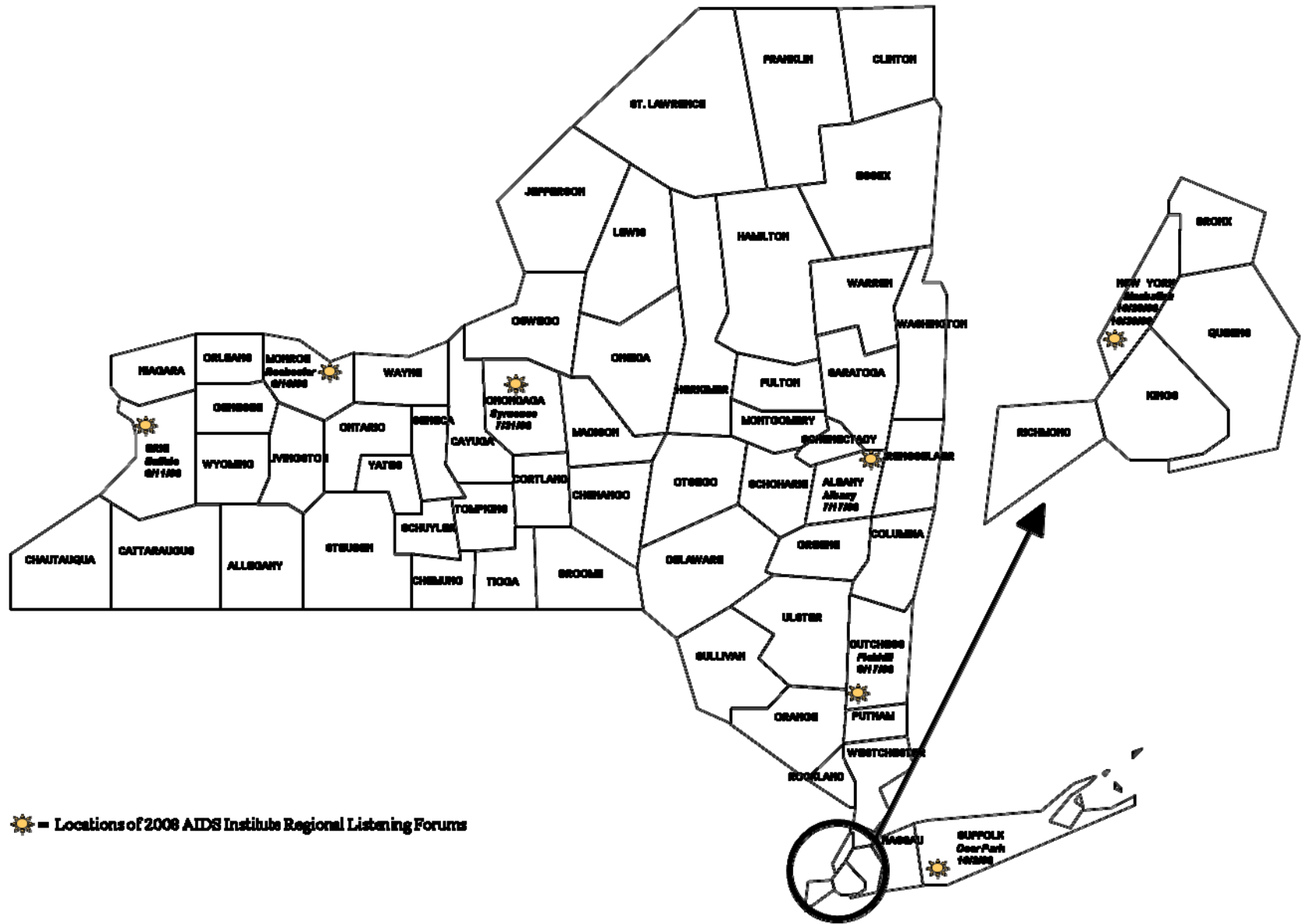
## **VII. Conclusion**

The listening forums were successful in informing the AIDS Institute of current issues and concerns throughout the State. They also provided an opportunity to present updates on the work being done by the AIDS Institute, reintroduce AIDS Institute staff to communities, and renew long-standing relationships with providers, consumers, and advocates. The AIDS Institute will continue to assess the results of the listening forums in relation to the AIDS Institute's strategic planning process. In addition, the needs identified and concerns raised in the listening forums will inform AIDS Institute policy and program development. Readers are encouraged to consider how they can advance the issues raised in the listening forums. In many cases, addressing specific issues requires concerted efforts of individuals, agencies, and organizations in addition to the AIDS Institute.

The AIDS Institute remains committed to keeping lines of communication open and to continuing its partnerships to collaborate effectively, address the issues at hand and accomplish mutual goals. Communication and consultation with consumers, providers, and others is extremely valuable to the AIDS Institute, especially in a rapidly changing, dynamic environment.

We thank all those who participated in the listening forums and those who submitted written comments.

Figure 1. Locations of AIDS Institute Regional Listening Forums, 2008



**Table 1. Regional Approach and Schedule of AIDS Institute Listening Forums, 2008**

<b>Region and Date</b>	<b>Counties/Boroughs Included</b>
<b>Rochester June 10, 2008</b>	Chemung, Livingston, Monroe, Ontario, Schuyler, Seneca, Steuben, Wayne, Yates
<b>Buffalo June 11, 2008</b>	Allegany, Cattaraugus, Chautauqua, Erie, Genesee, Niagara, Orleans, Wyoming
<b>Albany July 17, 2008</b>	Albany, Clinton, Columbia, Delaware, Essex, Franklin, Fulton, Greene, Hamilton, Herkimer, Montgomery, Otsego, Rensselaer, Saratoga, Schenectady, Schoharie, Warren, Washington
<b>Syracuse July 31, 2008</b>	Broome, Cayuga, Chenango, Cortland, Jefferson, Lewis, Madison, Oneida, Onondaga, Oswego, St. Lawrence, Tioga, Tompkins
<b>Hudson Valley September 17, 2008</b>	Dutchess, Orange, Putnam, Rockland, Sullivan, Ulster, Westchester
<b>Long Island October 2, 2008</b>	Nassau, Suffolk
<b>New York City October 29, 2008</b>	Bronx, Queens, Upper Manhattan
<b>New York City October 30, 2008</b>	Brooklyn, Staten Island, Lower Manhattan

**Table 2. Overview of Attendance at AIDS Institute Regional Listening Forums, 2008**

<b>Region</b>	<b>Clinical Providers</b>	<b>Consumers</b>	<b>Non-Clinical Providers</b>	<b>Total Attendees</b>
Rochester	8	22	21	51
Buffalo	16	25	25	66
Albany	7	13	22	42
Syracuse	8	22	25	55
Hudson Valley	12	40	30	82
Long Island	15	12	35	62
New York City	18	60	67	145
<b>Total</b>	<b>84</b>	<b>194</b>	<b>225</b>	<b>503</b>

**Table 3. Acronyms**

AAHIVM	American Academy of HIV Medicine
ADAP	AIDS Drug Assistance Program
ADHC	AIDS Day Health Care
AETC	AIDS Education and Training Center
AIDS	Acquired Immune Deficiency Syndrome
AIRS	AIDS Institute Reporting System
APG	Ambulatory Patient Group
ARV	Antiretroviral
ASO	AIDS Services Organization
CAC	Consumer Advisory Committee
CAT	Computerized Axial Tomography
CBO	Community-based Organization
CDC	U.S. Centers for Disease Control and Prevention
CEI	Clinical Education Initiative
CLAS	Culturally and Linguistically Appropriate Services
CME	Continuing Medical Education
CMS	U.S. Centers for Medicaid and Medicare Services
CMV	Cytomegalovirus
COBRA	Refers to the AIDS Institute COBRA case management program, also known as the Community Follow-up Program
DAC	Designated AIDS Center
DEBI	Diffusion of Effective Behavioral Interventions
DOCS	Department of Correctional Services
DOH	Department of Health
EMSA	Eligible Metropolitan Statistical Area
ESAP	Expanded Syringe Access Program
FEMA	Federal Emergency Management Agency
HASA	New York City HIV/AIDS Services Administration
HCV	Hepatitis C Virus
HIV	Human Immunodeficiency Virus
HIVMA	HIV Medical Association
HMO	Health Maintenance Organization
HOPWA	Housing Opportunities for Persons with AIDS
HRA	New York City Human Resources Administration
HRSA	U.S. Health Resources and Services Administration
LGBT	Lesbian/Gay/Bisexual/Transgender
LTHHC	Long Term Home Health Care
LTI	Leadership Training Institute
MCO	Managed Care Organization
MHHD	Minority Health and Health Disparities
MICA	Mentally Ill Chemical Abuser
MRI	Magnetic Resonance Imaging
MSM	Men Who Have Sex With Men

NIR	No Identified Risk
nPEP	Non-Occupational Post-Exposure Prophylaxis
NYC	New York City
NYS	New York State
NYSACHO	New York State Association of County Health Officials
OASAS	Office of Alcoholism and Substance Abuse Services
OMH	Office of Mental Health
OMRDD	Office of Mental Retardation and Developmental Disabilities
oPEP	Occupational Post-Exposure Prophylaxis
PEP	Post-Exposure Prophylaxis
PLWHA	Person(s) Living with HIV/AIDS
PPG	Prevention Planning Group
PSA	Public Service Announcement
RFA	Request for Applications
SAMHSA	U.S. Substance Abuse and Mental Health Services Administration
SASDC	Statewide AIDS Services Delivery Consortium
SBIRT	Screening, Brief Intervention, and Referral to Treatment
SEP	Syringe Exchange Program
SNP	Special Needs Plan
SSD	Social Security Disability
SSI	Supplemental Security Income
STD	Sexually Transmitted Disease
TB	Tuberculosis
TGA	Transitional Grant Area
YACAC	Young Adult Consumer Advisory Committee

# AIDS Institute Strategic Plan

2008 - 2010

	Innovative and Effective Organization	Data and Science-Driven Programs and Policies	Access to Care	Quality	Prevention	Leadership
<b>GOALS</b>	<p><b>Goal 1</b> Meet the needs of a dynamic and diverse population through organizational effectiveness and innovation.</p>	<p><b>Goal 2</b> Effectively use data and science to assess programs, develop new initiatives and target resources.</p>	<p><b>Goal 3</b> Provide early access to, and maximize utilization of, all services available under the AIDS service continuum.</p>	<p><b>Goal 4</b> Provide quality care, prevention and supportive services to improve the health and well-being of persons living with HIV and AIDS.</p>	<p><b>Goal 5</b> Prevent new infections and maintain health of those infected.</p>	<p><b>Goal 6</b> Advocate and lead in consultation with state, local and community-based organizations and with persons living with and at risk for HIV and AIDS.</p>
<b>OBJECTIVES</b>	<p>1.1 Effectively respond to new trends and challenges through innovative mechanisms that best meet the needs of diverse populations.</p> <p>1.2 Promote opportunities for staff development that encourage professional growth, support promotion and improve overall functioning.</p> <p>1.3 Maximize communication within the AIDS Institute and with external parties to facilitate knowledge sharing, and improve program effectiveness.</p> <p>1.4 Maximize available resources by streamlining AIDS Institute staff, functions and programs.</p> <p>1.5 Sustain existing and attract new resources.</p> <p>1.6 Continue efforts to hire qualified staff at all levels who are reflective of the communities most impacted and who are culturally competent.</p> <p>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.</p>	<p>2.1 Manage resources and develop programs on the basis of scientific evidence and objective data.</p> <p>2.2 Use data to target care and services and identify facilitators and barriers to care.</p> <p>2.3 Improve utilization of internal and external data for program development, evaluation and monitoring.</p> <p>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.</p> <p>2.5 Communicate research findings internally and externally to promote program development and ongoing improvement.</p> <p>2.6 Assure and promote the use of data collected by the AIDS Institute by providers, advisory bodies and others.</p>	<p>3.1 Assure that all persons living with HIV/AIDS have health coverage that promotes access to and retention in care.</p> <p>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.</p> <p>3.3 Engage hard to reach populations through collaboration with non-traditional providers and community stakeholders.</p> <p>3.4 Improve integration of health and social support services with input of external and internal partners.</p> <p>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.).</p> <p>3.6 Effectively utilize reimbursement mechanisms to encourage development of proficient health care services.</p> <p>3.7 Minimize disparities in access to and retention in care.</p> <p>3.8 Improve access to specialty and subspecialty services inclusive of HIV specialists, dental and mental health care and substance use treatment.</p> <p>3.9 Assure that health delivery systems promote access to quality care and evolve to meet emerging needs.</p> <p>3.10 Assure provision of supportive services necessary to ensure access to and retention in care.</p>	<p>4.1 Improve quality of care through evidence-based practices.</p> <p>4.2 Create and disseminate best practice standards and policies for HIV care, treatment, prevention and support services.</p> <p>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.</p> <p>4.4 Promote provider and consumer involvement in the development of and adherence to guidelines.</p> <p>4.5 Use quality improvement strategies to implement change.</p> <p>4.6 Regularly review quality programs to assure responsiveness to changing environments.</p>	<p>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.</p> <p>5.2 Collaborate with health care and community-based providers to reach populations at risk.</p> <p>5.3 Continue availability of comprehensive HIV education including knowledge of risk/harm reduction strategies.</p> <p>5.4 Promote evidence-based prevention approaches including increased use of condoms and sterile injection equipment.</p> <p>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.</p> <p>5.6 Target prevention programs and services using data and statistics and develop new strategies to reach diverse populations.</p>	<p>6.1 Coordinate the state's policies with respect to HIV and AIDS.</p> <p>6.2 Use policy research and science to guide program development and implementation.</p> <p>6.3 Propose, participate in and influence state, local and national HIV policy.</p> <p>6.4 Work with staff, providers, consumers, community members and elected officials on policy issues.</p> <p>6.5 Provide leadership to reduce stigma and discrimination associated with HIV/AIDS.</p> <p>6.6 Support and promote community leadership.</p> <p>6.7 Raise community awareness of policies and proposals that impact providers and persons living with HIV and AIDS in NYS.</p> <p>6.8 Promote leadership internally and externally (e.g., mentoring, internships, Leadership Training Institute).</p> <p>6.9 Learn from and include consumers and other relevant parties in HIV program development.</p>

## Mission, Vision and Framework

### 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.



## Strategic Plan Framework

New York State  
David A. Paterson, Governor

Department of Health  
Richard F. Daines, M.D.  
Commissioner

Office of Public Health  
Guthrie S. Birkhead, M.D., M.P.H.  
Deputy Commissioner

AIDS Institute  
Humberto Cruz, M.S.  
Director

July 7, 2009



**AIDS Institute Milestones  
1983 – 2008  
25 Year Commemoration**

**Dated:  
August 12, 2009**

- 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

Maternal/Pediatric Program

Chronic Care Initiatives

Supported Housing Programs

HIV/AIDS Materials Initiative

Committee for the Care of Children and Adolescents with HIV

**1989** “AIDS; New York’s Response, a 5-Year Interagency Plan”

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 1<sup>st</sup> Edition

Community Follow-Up Program

Legal Services Initiative

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

Nutrition Programs

Case Management Services

1<sup>st</sup> Statewide HIV/AIDS Conference

**1991** Informed Health Care Worker Policy

Ryan White Title II HIV CARE Networks

Pediatric/Adolescent Care Guidelines published

Enhanced Fees for Physicians

Transportation Services

2<sup>nd</sup> Statewide HIV/AIDS Conference

**1992** ADAP Plus  
Medical Protocols 2<sup>nd</sup> Edition  
  
Syringe Exchange Regulations filed and programs approved  
  
Multiple Service Agencies (MSAs) and Community Development Initiative (CDI)  
  
HIV services for HIV-positive women and families  
  
HIV Quality of Care Program  
  
Dental Standards of Care Committee  
  
3<sup>rd</sup> Statewide HIV/AIDS Conference  
  
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  
  
4<sup>th</sup> Statewide HIV/AIDS Conference

**1994** Statewide AIDS Service Delivery Consortium (SASDC)  
  
NYS HIV Prevention Planning Group (PPG)  
  
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)

5<sup>th</sup> 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

**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)

6<sup>th</sup> 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

7<sup>th</sup> Statewide HIV/AIDS Conference

**1998**

HIV Quality of Care Advisory Committee

Physicians' Prevention Advisory Committee

Treatment Adherence Initiative

HIV Reporting and Partner Notification Law

8<sup>th</sup> Statewide HIV/AIDS Conference

**1999**

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

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

9<sup>th</sup> 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

1<sup>st</sup> 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

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

2<sup>nd</sup> 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

3<sup>rd</sup> 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

4<sup>th</sup> 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**

15<sup>th</sup> Anniversary of Syringe  
Exchange in NYS

Condom Access Program

Plan for Enhanced Sexual Risk  
Reduction

AIDS Institute Reporting System  
(AIRS)

Health Alert Regarding 2<sup>nd</sup> Test in  
3<sup>rd</sup> Trimester

Defendant Testing Program

Best Practices – GYN Care

5<sup>th</sup> 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

Youth Consumer Advisory Council

“Responding to the Call” Faith  
Forum

Regional Listening Forums with

Consumers and Providers

6<sup>th</sup> Statewide Hepatitis C Conference

Governor Proclamations  
Recognizing the AIDS Institute and  
the AIDS Advisory Council

## APPENDIX 3

### Links to Resources

About the AIDS Institute

<http://www.nyhealth.gov/diseases/aids/about/index.htm>

Interactive On-line HIV Patient Resources Directory

[http://www.nyhealth.gov/diseases/aids/resources/resource\\_directory/patient\\_resources\\_directory.htm](http://www.nyhealth.gov/diseases/aids/resources/resource_directory/patient_resources_directory.htm)

2006 NYSDOH AIDS Institute Resource Directory

[http://www.nyhealth.gov/diseases/aids/resources/resource\\_directory/index.htm](http://www.nyhealth.gov/diseases/aids/resources/resource_directory/index.htm)

HIV Counseling & Testing Resource Directory - 2004 Revised Edition (January 2008 Update)

<http://www.nyhealth.gov/diseases/aids/testing/directory/index.htm>

Syringe Exchange Programs

[http://www.nyhealth.gov/diseases/aids/harm\\_reduction/needles\\_syringes/docs/sep\\_hours\\_sites.pdf](http://www.nyhealth.gov/diseases/aids/harm_reduction/needles_syringes/docs/sep_hours_sites.pdf)

Expanded Syringe Access Program Sites

[http://www.nyhealth.gov/diseases/aids/harm\\_reduction/needles\\_syringes/esap/provdirect.htm](http://www.nyhealth.gov/diseases/aids/harm_reduction/needles_syringes/esap/provdirect.htm)

Community Sharps Collection Sites

[http://www.nyhealth.gov/diseases/aids/harm\\_reduction/needles\\_syringes/sharps/directory\\_sharpscollection.htm#directory](http://www.nyhealth.gov/diseases/aids/harm_reduction/needles_syringes/sharps/directory_sharpscollection.htm#directory)

Opioid Overdose Prevention Programs

[http://www.nyhealth.gov/diseases/aids/harm\\_reduction/opioidprevention/programdirectory.htm](http://www.nyhealth.gov/diseases/aids/harm_reduction/opioidprevention/programdirectory.htm)

2009 Statewide Coordinated Statement of Need and Comprehensive Plan

<http://www.nyhealth.gov/diseases/aids/reports/scsn/index.htm>

New York State Condom (NYSCondom) Program

<http://www.nyhealth.gov/diseases/aids/facts/condoms/nyscondom.htm>

Statewide HIV/AIDS Training Calendar July - December 2009

[http://www.nyhealth.gov/diseases/aids/training/docs/calendar\\_july-december\\_2009.pdf](http://www.nyhealth.gov/diseases/aids/training/docs/calendar_july-december_2009.pdf)

HIV Clinical Education Initiative

<http://ceitraining.org/>

Clinical Guidelines

<http://www.hivguidelines.org/Content.aspx?pageID=1>

HIV Uninsured Care Programs - Summary

<http://www.nyhealth.gov/diseases/aids/resources/adap/index.htm>

HIV Special Needs Plans (HIV SNPs)

<http://www.health.state.ny.us/diseases/aids/resources/snps/index.htm>

Medicaid Program

[http://www.nyhealth.gov/health\\_care/medicaid/](http://www.nyhealth.gov/health_care/medicaid/)

OASAS Treatment Provider Search and Directory

<http://www.oasas.state.ny.us/treatment/directory.cfm>

OASAS Addiction Medicine Web Site

<http://www.oasas.state.ny.us/AdMed/index.cfm>