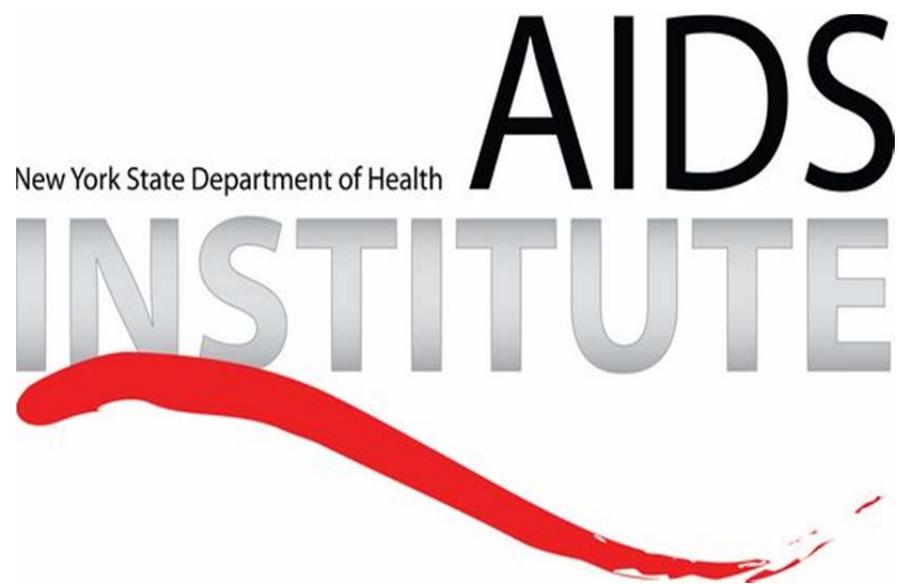


2011 Regional Listening Forums



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 May and July 2011. The listening forums were conducted as part of the AIDS Institute's strategic planning.

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 distinct regional issues and concerns. Regional listening forums offer an opportunity for smaller, open discussions and acknowledge the significant variation across regions. Two sessions were held in each region: a morning session with providers and clinicians; and an afternoon session with consumers. This approach recognized and accommodated a diversity of perspectives and concerns.

Invitees received letters from Mr. Cruz encouraging attendance to provide their perspectives 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 before or at the listening forums.

More than 300 consumers and providers attended the listening forums. Senior staff of the AIDS Institute attended each forum to listen, to provide 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.

The 2011 forums differed from the 2008 forums in that they were in the form of a dialog. In 2008, the AIDS Institute listened to the concerns of providers and consumers. In 2011, in the midst of a changing service delivery environment, the AIDS Institute responded to the concerns of providers and consumers and provided as much information as possible on the changes, particularly with regard to Medicaid, that will affect consumers and providers.

II. 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. 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. The successes resulting from the HIV/AIDS infrastructure that has been developed during 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 11 new HIV infections in NYS every day, and nearly five New Yorkers with HIV/AIDS die every day. Program highlights and future challenges are described in Appendix 1: *AIDS Institute: Successes and Challenges*.

The “AIDS Institute Milestones” (Appendix 2) is an overview of the history of HIV/AIDS issues, policies and programs. 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’s strategic planning helps make sure programs and services effectively meet identified needs. The listening forums are an essential component of this process.

III. Overarching Issues

In compiling this report, the AIDS Institute identified that some important, overarching issues raised are larger issues, not specific to HIV/AIDS. Forum participants noted that these issues directly affect persons living with HIV/AIDS (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, specialty care, and supportive services; lack of access to HIV-experienced clinicians.
- **Budget Reductions:** Reductions in funding from all sources are affecting HIV/AIDS services and providers.
- **Health Care Reform:** Uncertainty about the impact of health care reform on providers and consumers.
- **Medicaid Redesign:** Uncertainty about the impact of Medicaid redesign and the implementation of health homes on PLWHA and providers, particularly COBRA case management providers.
- **Mandatory Medicaid Managed Care:** Concern about the implementation of mandatory Medicaid managed care statewide.
- **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:** 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.
- **Housing:** Housing status influences HIV risk, access to and retention in care, and health outcomes.
- **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.
- **Employment:** The needs of persons living with HIV/AIDS in the workplace.
- **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 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.

IV. Summary of Statewide Concerns

This section summarizes the concerns discussed during the listening forums in each region. While certain issues were specific only to one region, most comments indicated statewide problems and concerns. The AIDS Institute will continue to consider ways to address or influence these issues.

NOTE: A more detailed report of the concerns voiced in each region is available. If you would like to request a copy of the report that includes region-specific issues, please call Angela Rivera-Maycole at (518) 474-6399, or send an e-mail to axr12@health.state.ny.us.

Prevention

Participants at all forums discussed the role of prevention and harm reduction education – how messages have changed, how activities should change, and what should be kept. Messages should target subsets of the population, including schoolchildren, people of color, heterosexual women, the 50-and-older population, people in the criminal justice system, LGBT people of color, and those with substance abuse or mental illness, for example. The same message does not work for everyone, and with the epidemic continuing to spread, an intergenerational approach should be considered.

To clarify the discussions, AIDS Institute staff noted that harm reduction strategies can be used to reduce HIV and STD transmission rates among people who have already chosen to engage in risky behaviors, but harm reduction does not condone risky behaviors. For example, syringe access and exchange programs have helped lower the proportion of injection drug users (IDUs) among newly diagnosed cases from 54 percent in 1992 to 4 percent in 2010. Harm reduction training programs should be examined to ensure that workers will be able to tailor messages to the individual seeking help.

Providers and consumers agreed that incorporating STD and hepatitis prevention and treatment into the AIDS Institute's programs made organizational and programmatic sense. These programs had been administered by other bureaus in the State Department of Health.

Participants agreed that having people who are HIV-positive deliver prevention messages in peer training – “prevention with positives” – was helpful. One speaker suggested asking clients newly diagnosed with HIV whether something could have been said or done to prevent their infection. People living with HIV/AIDS (PLWHA) are often very willing to speak out to help prevent the spread of the disease.

Many felt more should be done to enforce the mandate for HIV education in schools. As health and wellness curriculums evolve, sexual health should be incorporated. Some advocated a socio-cultural model of wellness education that would include emotional, mental, spiritual and community health, as well as sexual health.

AIDS Institute staff said they have seen a 44 percent reduction in infection in at-risk people who have had pre-exposure prevention (PrEP) counseling. To build on this type of success, staff indicated that workers will need to expand their toolkit of messages to help people protect themselves from infection. Similarly, more people at risk need to learn about post-exposure prophylaxis (PEP). Some participants were concerned that the new PrEP studies take focus away from vaccine trials, which should be encouraged, even though the State does not finance them.

Participants also offered views on whether the federal Centers for Disease Control and Prevention (CDC) should consider HIV to be a standard communicable disease, given that the epidemic is more than 30 years old. Speakers were concerned that as New York succeeds in reducing new infections, its federal funding is reduced, limiting new approaches in prevention and other services.

HIV Testing

Providers and clients reacted positively to the expanded HIV testing law, which took effect in September 2011 and requires doctors providing primary care to offer HIV testing to their patients. People are learning, slowly, that the doctor's offer of an HIV test is not an accusation.

Participants thanked AIDS Institute staff for their approach, implementing the testing initiative as a standard of care. The community accepts testing, and that will drive more efforts to get newly identified HIV-positive people connected to care. Partner services will need to be enhanced.

Hospital emergency departments were doing well implementing the new law, participants said. Some primary care and subspecialty physicians have concerns or do not realize they must offer testing. The AIDS Institute continues to offer an hour-long clinical education training for providers, with a clinician hotline at 1-866-637-2342 and an email address for questions at HIVtestlaw@health.state.ny.us.

Participants asked the AIDS Institute to consider a "Dear Colleague" letter to encourage adherence with the law, and to consider public service announcements on why front-line providers must offer testing. Participants suggested that rapid testing is needed for STDs, as it is for HIV and hepatitis C.

AIDS Institute staff acknowledged that there were no resources attached to the law when it took effect in September 2011 and asked participants to let them know whether implementation is going well or poorly.

Some people do not value themselves, and if they do not, who cares if they die of HIV. We need to motivate people to take care of themselves and protect their partners.

AI staff cited a USA today article describing how even 30 years after the epidemic began, many are still getting diagnosed with HIV and AIDS at the same time because of late diagnosis; this underscores the need for testing.

Health Care

Initiation of Care

Several participants referenced a new study indicating that early initiation of care with proper medication management can significantly reduce HIV transmission rates – making treatment an effective means of prevention. AIDS Institute staff said that research is under review. Current guidelines recommend initiating treatment at 500 CD4 or less. A change in that policy at the state or federal level would affect immediate costs for medications and staffing and would need to be evaluated against savings realized by avoiding transmission. AIDS Institute staff noted that New York does not have a waiting list for ADAP, but other states do, and the recommended federal increase in the program is only \$23 million.

Providers are seeing an increase in young people, with an average age of 25, many with complex psychosocial needs – substance abuse, mental health issues and poverty – as well as acute medical problems. The competing needs often lead to non-compliance with medications, despite a clinician’s best effort.

Access to Care

Rural residents said the lack of primary care coverage is a major issue. Some patients in the North Country must go to Vermont for medical care. Some rural providers send HIV-positive patients to AIDS treatment centers miles away, even for an emergency non-HIV issue, such as a broken ankle, because they believe they are not equipped to help. Some clinicians said long-term care providers are not receptive to PLWHA in nursing homes or home care, causing patients to travel long distances or have gaps in service. Consumers asked the AIDS Institute to encourage rural providers to use the consultation line to communicate with AIDS treatment centers.

Some consumers are concerned about their elected officials’ lack of knowledge about HIV in their own cities. Often, these are locations where PLWHA must travel long distances to access care. Having too few providers creates transportation issues for consumers, especially for acute illnesses, because transportation must be arranged in advance.

Further, fewer clinicians are choosing to pursue HIV care as experienced providers retire. More providers need experience managing antiretroviral therapy, especially as PLWHA are living longer.

AIDS Institute staff noted that Medicaid redesign includes the development of health homes to provide care management and support to help people engage and stay in care, as well as behavioral health organizations to integrate mental health and substance abuse services. This is a different care model than the designated AIDS centers, but the time has come for new models to address problems such as those discussed at the listening forums. Staff acknowledged that the Institute needs to do more work to address the aging of the epidemic. The AIDS Institute is working on projects with the federal government to use mentors to increase the number of HIV service providers in shortage areas and to identify patients’ locations and nearby services.

Pain Management

Some consumers complained that pain is not managed effectively because some doctors are hesitant to prescribe medications out of concern that patients could become addicted to pain medication. AIDS Institute staff advised that the State Office of Alcoholism and Substance Abuse Services is leading a 20-agency effort to write standards on pain management in people using opioids.

Chronic Disease Model

Participants were concerned that a future decision to apply a chronic disease model to HIV could erode HIV services developed with the AIDS Institute over decades of the epidemic. HIV still is viewed with stigma; one participant noted that no one will ask how a person became diabetic, but they will ask how a person became infected with HIV. Participants supported services assisting in medical case management, treatment adherence and mental health.

AIDS Institute staff at the forums said the care and support systems created for HIV must be expanded to meet other needs. HIV is no longer a singular disease; people with HIV have other conditions. The HIV epidemic has “bookends” in New York – older and younger New Yorkers are heavily affected, with young people feeling immortal and older people feeling prevention fatigue.

Other

Forum participants offered comments on the following issues:

- If more pharmacies participate in pre-packaged medications, patient compliance likely would increase. Some consumers have difficulties with mail-order pharmacies.
- Supporting primary care models that support medical case management, treatment adherence and mental health services will help reach the National HIV/AIDS Strategy goals.
- Finding dental care providers remains an issue. The AIDS Institute is compiling a service directory and working with dental schools.
- Some regions do not have enough mental health service providers who accept Medicaid or ADAP as payers. Depression and PTSD are very real concerns for PLWHA, and stress taxes the immune system.

Health Care Coverage and Reimbursement

Consumers praised ADAP and ADAP Plus for its help with the cost of medication and mental health services for people who are ineligible for Medicaid and have no other health insurance.

Participants are concerned about the impact of Medicaid’s move to managed care on patients and providers. Several providers felt that Medicaid’s 2009 transition to Ambulatory Patient Group (APG) reimbursement weakened the provider community and eroded specialty care for patients. Now, all Medicaid patients will be put in a care management program over the next three years. Uncertainty causes unease. AIDS Institute staff said the APG rates are comparable to the former system and reflect the complexity of the diagnosis and number of procedures.

AIDS Institute staff advised consumers to ask their providers which managed care plans they work with so that when consumers recertify for Medicaid, they will know which plan to use. Patients should also call the plans to find out how their processes work. AIDS Institute staff is educating providers about the coming changes so they can discuss them with patients. Managed care plans will be required to have all classes of drugs in their formularies, including antiretroviral therapy. Mental health and substance abuse inpatient services will be provided through regional behavioral health organizations, to be established over the next two years. Staff encouraged the community to monitor the AIDS Institute and Medicaid Redesign Team web sites, and to consult Empire Justice Center and AIDS Community Resources, which have contracted with the state to help consumers make their managed care choices. The AIDS Institute is working with the NYSDOH Office of Health Insurance Programs to identify regional patterns of HIV care to avoid scenarios where people have to change their HIV provider because the provider is outside the patient's county of residence.

Consumers were also concerned about health insurance exchanges, coming in 2014, and their effect on costs. AIDS Institute staff said a lot of consumer education will be available during the next two years. Community Health Advocates is working on an education campaign with the Community Service Society, Empire Justice Center and Legal Aid Society. Two of the subcontractors for the campaign are HIV-specific: GMHC in New York City and AIDS Care in Rochester.

Providers and consumers wanted information on health homes, a program that is part of federal health care reform. Health homes will provide a care coordination model for high-cost, high-need Medicaid recipients. New York has specified that PLWHA will be eligible for health homes. The AIDS Institute is recognized for its effective groundbreaking work on care coordination and is working with staff responsible for health homes in New York. Targeted HIV/AIDS case management (COBRA) programs will be converted to health homes. The web site http://www.health.ny.gov/health_care/medicaid/program/medicaidhealthhomes describes the program and contains draft standards.

Hepatitis C (HCV)

Participants agreed that providers need enhanced education on the care and treatment of patients with hepatitis C. Consumers are surprised at the new treatments and need to voice the demand for hepatitis C funding. More people are dying of hepatitis C than HIV/AIDS. Consumers thanked the AIDS Institute for new funding for hepatitis C co-infection services, adding that more information needs to be readily available. Some consumers suggested combining information from publications on HIV, STDs and HCV and give people a frank picture of the risk of co-infection. Young people with STDs are at risk for becoming HIV-positive.

Medicaid will pay for the new hepatitis C medications, but ADAP does not have the resources to cover them. AIDS Institute staff said the federal government has developed a hepatitis C plan but has not made funding available. Providers were pleased that the AIDS Institute has a demonstration project on the rapid hepatitis C test, using the model of service delivery created for HIV/AIDS. The U.S. Food and Drug Administration has not approved the HCV rapid test yet. However, if testing is expanded and more people are found to be infected, there may not be enough treatment slots, particularly for low-income people. And the new treatments would cost about \$50,000 for the full course to treat HCV type one, which has not responded well to current treatments.

Some consumers thought that just as HIV-positive people have effectively delivered prevention messages, perhaps some HCV-positive people would want to share their stories. Some consumers said people are not aware that there are effective vaccines for hepatitis A and hepatitis B.

Sexually Transmitted Diseases (STDs)

Universally, providers and consumers were concerned about the rising rate of STDs in New York. In some counties, only one clinic tests for STDs, which severely affects other providers, and drives the need for more treatment resources. Several advocated for expanded STD screening in non-traditional settings.

Consumers, clinicians and providers indicated they were pleased that the AIDS Institute had assumed responsibility for STDs, which, like HIV, cause people to suffer from stigma and discrimination. One provider representative said the integration of the programs has allowed for increased staffing so that more patients can be seen.

Attendees acknowledged that prevention messages have to encourage testing and treatment as well as condom use and other preventive measures.

Supportive Services

Housing

Many participants emphasized the need for stable housing arrangements. AIDS Institute staff said the Medicaid Redesign Team is considering a New York New York IV phase that would add 5,000 beds outside New York City, of which some would be set aside for PLWHA. The Redesign Team will hold public meetings on their proposals. MRT has a work group looking at housing needs for people with chronic illness.

A consumer said the federally funded housing in his/her city is hard to get into, has zero tolerance for drugs and alcohol, its identification with HIV status is becoming problematic, and rent has increased. In general, participants agreed that people are afraid of the stigma and discrimination of living in a building known as HIV/AIDS housing.

Affordable housing is a big issue in urban and suburban counties.

Transportation

Many saw limited access to reliable transportation as a barrier to care, making it difficult to keep medical appointments and support group meetings. AIDS Institute staff noted that New York is changing how Medicaid transportation is managed and will contract directly with vendors across the state for regional programs.

Some regions said that transportation access has improved since the issue was raised at the listening forums three years ago. Transportation continues as a high priority, especially in rural areas where consumers have no other means of travel. Poor transportation options can create acute social isolation,

which decreases treatment adherence. Inadequate transportation and excessive travel times were cited by providers and consumers.

Family Support

A provider representative discussed Positive Families, which provides supportive services for families to work through the difficult emotional barriers of working through disclosure and the legal system barriers that can take a long time to resolve.

Nutritional Support

People emphasized the need for good nutrition to maintain clients' health, with praise for programs such as Meals on Wheels. A provider representative said a waiting list had to be set up because there isn't enough funding.

Translation Services

Consumers said more American Sign Language and Spanish translation services are needed, especially in training, education and advocacy programs.

Loss of Local Network

Some consumer advocates noted the termination of the local networks and said the networks helped advocates communicate with consumers, sharing information throughout the community while maintaining confidentiality. The network's consumer advisory committees also gave an avenue to provide input. AIDS Institute staff noted that ending the networks was difficult, but direct services have to be the priority when facing budget cuts. The Institute has a directory of social media web sites that can help consumers and providers alike.

Support groups for affected individuals were an early effort to help PLWHA talk with each other. The need to connect is still there, even as the epidemic evolves. Some community members said they were trying to figure out a way to support grassroots initiatives to help provide a venue for HIV-positive individuals to connect. Child care for attendees is a particular need in some areas. PLWHA also need family support to help them face the stressors affecting them all.

Case Management

A provider representative said case managers help people find medical providers and make sure clients stay in care. Without case managers, clients might not follow up with treatment, which hurts their health outcomes.

Non-medical case management is also important to the community, and people were concerned about the coming changes for COBRA case management programs. Case management has played a major role in stabilizing the lives of thousands of people.

AIDS Institute staff reminded people that AIDS services have continually changed over the years, and providers have to be part of the changes coming with Medicaid Redesign and federal health reform.

New York's Medicaid program is tapping into the AIDS Institute's expertise as it designs the health homes program, which will address individuals' needs in a larger context than the HIV/AIDS model. Providers were advised to attend the public meetings with the Office of Health Insurance Programs for further discussions on health homes, the future of COBRA programs and reimbursement.

Employment

Providers noted that once clients get the basic needs – housing, getting to treatment, and mental health services – many want to get back to work, back to life, and learn skills that help them in the community so they can be productive and useful. AIDS Institute staff updated participants on the HIV Employment Pilot Project, implemented in December 2010 with the State Departments of Labor and Education, and community-based organizations funded by the AIDS Institute. Employment, vocational and training services for PLWHA will be offered in selected Department of Labor One-Stop Career Centers in lower Manhattan, the Bronx and Rochester, with providers sharing referrals and cross training staff. The Working Disabled Program helps people keep their Medicaid benefits when they return to work.

It is difficult for people to get back into the working world when they are behind in their taxes or student loan payments and find that the government takes more of their earnings. Loan forgiveness for the disabled should be considered, because working people benefit the tax structure when they are no longer on Supplemental Security Income or Social Security Disability benefits. As people improve with treatment, they want to go back to work or school to be productive.

Education and Outreach

Participants in several regions said the clinical education initiative plays a vital role, including training on the new HIV testing law, continuing education for clinicians on STDs and enhancing clinician skills in treating acute HIV. Providers suggested additional education on HIV/AIDS for providers who are not directly related to HIV service provision would be beneficial.

Mentoring from an experienced consumer was cited as essential to consumer training. Additional resources for immigrants and refugees were recommended. Engaging church organizations was suggested, as well as a growing need for effective outreach to older people.

More literature and trainings should be available in Spanish.

A provider representative said when youth organize events, they can get their peers to attend. Several consumers were concerned about the lack of knowledge among young people. AIDS Institute staff agreed that education needs to reach youth, but also must reach teachers and parents who are in the youth environment. Education is the best way to reduce transmission, but HIV/AIDS is transmitted through sex, people do not want to talk about sex, and too many do not support sex education. A consumer suggested continuing education for school board members to encourage testing in school.

Some older PLWHA said the older population cannot be ignored.

Not enough organizations are able to reach youth in the MSM community to educate them on preventing transmission. Similarly, at times, the transgender community feels left on its own, encountering barriers because people do not know how to address uncomfortable topics.

Consumers suggested that people ask their doctors to keep up to date on HIV/AIDS, noting that an emergency department might not know the difference between pneumocystis and pneumonia, but a primary care physician would with proper education. AIDS Institute staff noted that this is a model the Institute is interested in pursuing.

Providers and consumers emphasized the importance of social networking, as social media is used for hooking up. Social media is replacing the physical drop-in center with a computerized one. Federal funding must be used on direct services, which has caused funding for local networks to be cut. The AIDS Institute is encouraging the use of social networking through computerization as an alternative. Social networking can help people navigate the service system.

Organizational, Policy and Administrative Issues Affecting Care and Service Delivery

Many providers said the management of state and federal grants has become quite complex. Paperwork requirements have become excessive and burdensome. Federal monitoring standards are multiplying, which will require more work related to monitoring and reporting. A provider with multiple grants asked whether the fiscal monitoring could be centralized so that the provider doesn't have to address the same issue with numerous monitoring teams. Institute staff said centralized monitoring is being considered, and that they are working to make the federal Health Resources and Services Administration (HRSA) aware of the burden their new standards are imposing on providers. HRSA recently issued more than 200 pages of more than 300 monitoring standards.

Some providers said the decentralization of contract management makes it difficult to integrate care. So many things are changing at once – mental health services, Medicaid reimbursement, Ryan White funding. This challenges providers significantly.

Several providers expressed frustration over the lack of cooperation and information sharing from the federal Veterans Administration. AIDS Institute staff explained its work with the President's Advisory Council on HIV/AIDS and the U.S. Department of Health and Human Services to secure better cooperation.

Some consumers were discouraged by treatment from their local departments of social services, the staff of which often do not know what PLWHA go through every day. PLWHA often detect negative attitudes from social services staff and a lack of training.

On the other hand, participants said their relationships with AIDS Institute contract managers have improved to become more like partnerships.

More time was requested for responding to Requests for Applications (RFAs) and Continued Funding Applications (CFAs) so that more thorough responses can be prepared.

Progress in the AIDS Institute Reporting System (AIRS) was noted, particularly in the availability of AIRS staff. AIDS Institute staff said it was continuing to explore ways to make AIRS compatible with other databases to eliminate double data entry.

Stigma and Confidentiality

Despite decades of experience educating the population about HIV/AIDS, stigma lingers, affecting consumers' dignity and their willingness to adhere to treatment. Some consumers noted that their medical files have stickers identifying them as a PLWHA, even though that violates patient confidentiality. Similarly, people are reluctant to seek services when the providers' offices are referred to as the "AIDS building."

As agencies that are not HIV-specific are asked to take on services for PLWHA, more education is needed. These new providers are fearful. At times, providers step back once the patient mentions HIV.

Several providers discussed stigma in the Black community, saying that just knowing someone has AIDS brings stigma. Similarly, a provider representative said that in a support group for HIV-positive gay men in their 40s and 50s, participants worry how their families and friends will perceive them.

Some consumers say the stigma of STDs is, in some cases, overtaking the stigma of HIV.

Special Populations

Substance Users

A provider commented that health insurers are resistant to clients entering substance abuse rehabilitation. This is further complicated by some PLWHA feeling misunderstood in the rehab environment because certified alcohol and substance abuse counselors do not receive special training in HIV/AIDS. Some participants asked whether HIV could be part of the counselors' continuing education and re-credentialing process.

A physician discussed the difficulty in treating pain in patients with drug-seeking behavior or a history of substance abuse. The State Office of Alcoholism and Substance Abuse Services is leading an effort to write standards on pain management in people using opioids.

Another provider representative was concerned over the sale of prescription medications and advocated drug testing to deter use of street-level narcotics. Another asked what collaborations are going on between HIV/AIDS and substance addiction programs. AIDS Institute staff said that in the 1990s, the Institute developed primary care in substance use treatment programs, and has implemented harm reduction programs to link substance use and HIV issues. In addition, opioid overdose prevention programs have been implemented.

AIDS Institute staff reminded participants that at one time, the epidemic in New York was driven by substance use. The availability of needle exchange programs has reduced incidence among intravenous drug users, and they now are more likely to acquire HIV through sex than through drug-use activities.

Other participants called attention to adolescents who are substance users, and urged that more training and peer education be directed to this area. Current models of care do not meet the needs of teen runaways who prostitute themselves to buy drugs. Once they are infected with HIV or hepatitis C, they are likely to transmit the viruses.

Other consumers said substance abuse services in some communities do not recognize different cultures when planning prevention education programs.

Mentally Ill

The need for more mental health services was widely discussed in all regions. Some participants felt many therapists have fear about HIV, making it difficult to find therapists sensitive to HIV/AIDS issues and able to support PLWHA. Consumers with mental health issues face long waiting lists if they can find a provider that accepts their insurance. Other participants questioned whether the mental health field is prepared to work with PLWHA who are dually or triply diagnosed.

AIDS Institute staff noted that Medicaid redesign includes behavioral health organizations and behavioral health special needs plans that might ease this problem.

Others noted that while primary care physicians can identify mental health issues, they are not equipped to treat them. Training is needed on crisis intervention.

Providers note that they see consumers with depression and social isolation, which are among the effects of stigma. Just like anyone else, a PLWHA may also be diagnosed with bipolar disorder, and the management of stress becomes paramount because it affects health and viral load.

Some consumers do not need one-on-one mental health care long term, but suffer instead from conditions such as suicidal tendencies in which crisis intervention and short-term therapy would be effective – if they could find a provider.

Children

In some areas of the state, participants said more options for pediatric health care are needed, citing areas with one site or only one doctor who visits twice a month. AIDS Institute staff acknowledged that the epidemic has shifted from children to adolescents, and resources are limited. They suggested finding a pediatrician with admitting privileges at a hospital that also serves as an AIDS Center, so that the pediatrician can get more information.

Adolescents and Youth

A provider praised efforts to train youth in patient self management, empowering youth to gain knowledge. Too many youth believe that there will be medication that controls or cures the disease, and do not protect themselves properly because they feel invulnerable.

Aging Populations

The aging of PLWHA was raised as an issue in community care and in nursing home care. AIDS Institute staff noted that almost 76 percent of PLWHA are 40 years old and older, and nearly 40 percent are 50 and older. As PLWHA age, they are affected by chronic diseases such as diabetes, complicating their overall treatment plans. Initiatives to battle chronic disease are being folded into federal health care reform and Medicaid redesign in New York, and the unique needs of PLWHA will have to be addressed. Health homes and other models of care will help older PLWHA.

Communities of Color

In some regions, elected officials are becoming aware of the rising infection rate within the African American community, and are reaching out to consumer advocates.

CDC guidelines for funding are specific and make funding for heterosexuals, particularly people of color, difficult to obtain because they are often categorized as “no identified risk” (NIR). AIDS Institute staff said the Institute is part of the national dialogue to persuade CDC to change its NIR category, which has masked the heterosexual epidemic, particularly for heterosexual women.

A consumer stated that risky behaviors for African American and Latino teens start by 16. Outreach must be tailored to subcultures within cultures, with age and gender among the factors.

Men Who Have Sex With Men (MSM)

Some regions noted that young MSM are coming to care already diagnosed with AIDS and syphilis, are doing sex work, suffered sexual abuse as children and do not use condoms.

AIDS Institute staff clarified that all its RFAs have specific population-based targets, with most interventions targeted to African Americans, Latinos or other minorities. Many of these target young MSM. The specificity is needed because general services do not reach young people.

The Formerly Incarcerated

Questions from participants focused on the State’s efforts to provide continuing services for HIV-positive inmates upon their release from prison. AIDS Institute staff explained that a new effort to help inmates transition into communities was being funded through five contract organizations. Testing and interventions are provided for HIV and hepatitis C. ADAP is also working to provide transitional services. Medicaid eligibility is suspended while inmates are in prison, but those who had been eligible for Medicaid before incarceration can continue on Medicaid after release.

The Deaf and Hard of Hearing

A consumer said language and communication to reach people who are deaf or hard of hearing is the biggest issue. More American Sign Language interpreters are needed, but they have to be at medical or case management appointments, as well as at education and advocacy programs. The logistics are difficult. Many deaf people are not bilingual in English or cannot read. This makes social media less effective in educating this group than other special populations.

V. Conclusion

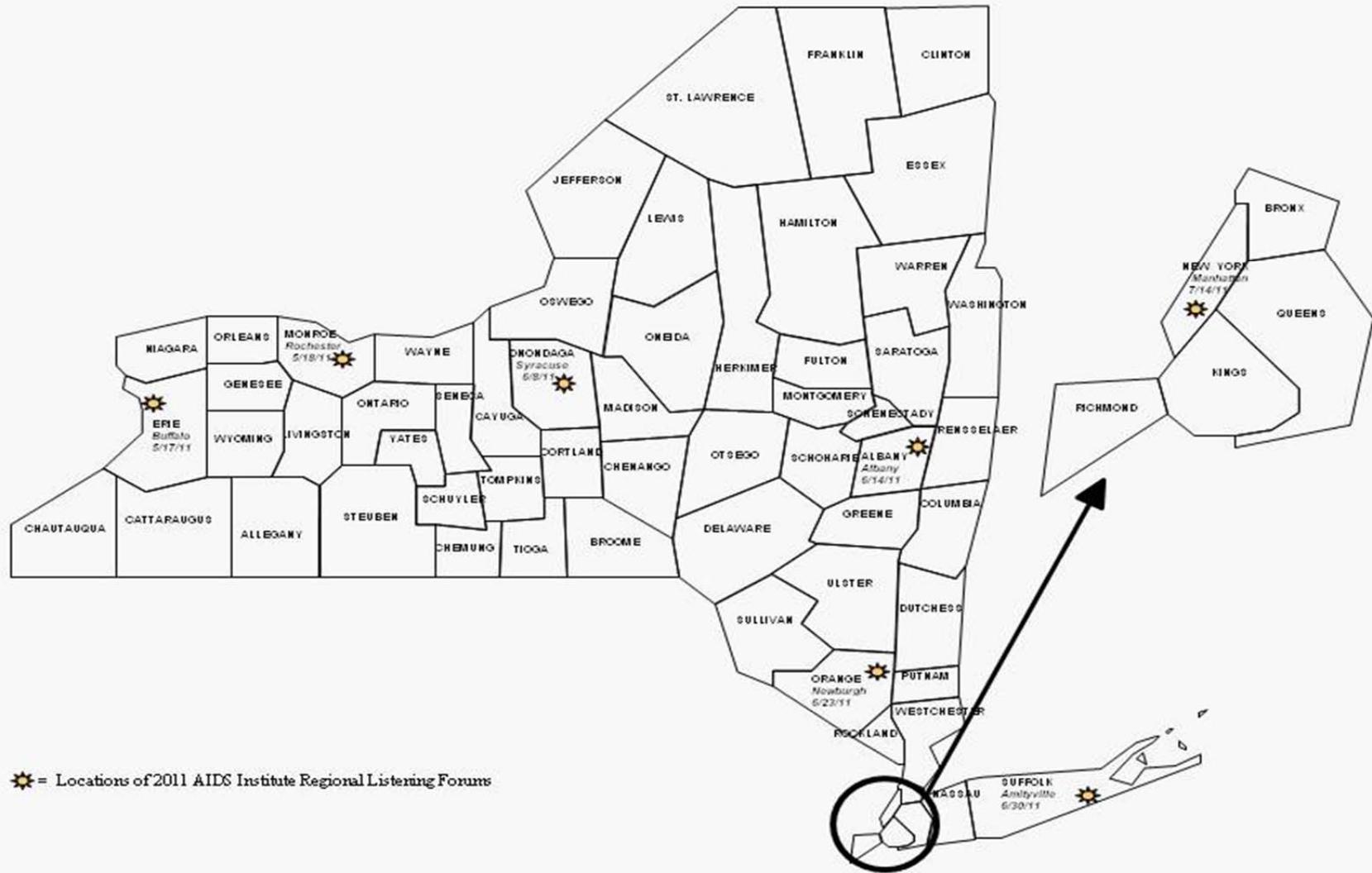
The listening forums successfully informed the AIDS Institute of current issues and concerns throughout the State. They also provided an opportunity for the Institute to present to the community updates on work being done by the AIDS Institute; present updates on mandatory Medicaid managed care, Medicaid redesign in NYS, and health homes; 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, 2011



Prepared by the New York State Department of Health, AIDS Institute
May 16, 2012

Table 1. Regional Approach and Schedule of AIDS Institute Listening Forums, 2011

Region and Date	Counties/Boroughs Included
Buffalo May 17, 2011	Allegany, Cattaraugus, Chautauqua, Erie, Genesee, Niagara, Orleans, Wyoming
Rochester May 18, 2011	Chemung, Livingston, Monroe, Ontario, Schuyler, Seneca, Steuben, Wayne, Yates
Syracuse June 8, 2011	Broome, Cayuga, Chenango, Cortland, Jefferson, Lewis, Madison, Oneida, Onondaga, Oswego, St. Lawrence, Tioga, Tompkins
Albany June 14, 2011	Albany, Clinton, Columbia, Delaware, Essex, Franklin, Fulton, Greene, Hamilton, Herkimer, Montgomery, Otsego, Rensselaer, Saratoga, Schenectady, Schoharie, Warren, Washington
Hudson Valley June 23, 2011	Dutchess, Orange, Putnam, Rockland, Sullivan, Ulster, Westchester
Long Island June 30, 2011	Nassau, Suffolk
New York City July 14, 2011	Bronx, Queens, Brooklyn, Staten Island, Manhattan

Table 2. Overview of Attendance at AIDS Institute Regional Listening Forums, 2011

Region	Providers/ Clinicians	Consumers	Total Attendees
Western	24	17	41
Finger Lakes	21	14	35
Central	39	12	51
Northeast	21	20	41
Hudson Valley	20	24	44
Long Island	20	11	31
New York City	40	26	66
Total	185	124	309