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Assessing Needs, Gaps, and Barriers

New York Integrated HIV Prevention and Care Plan 2017-2021

REGION	Northeast
PLAN TYPE	Integrated state/city/county prevention and care plan
JURISDICTIONS	State of New York, New York City EMA, and Nassau County EMA
HIV PREVALENCE	High

New York State’s needs, gaps, and barriers section is very detailed and breaks down the service needs and gaps in great detail, including the key needs identified by the individual New York City Boroughs and several regions of the State. They described their process to identify key stakeholders and ensure fair representation of the various demographics in the state. This process could be for other states that have a large urban hub as well as a more dispersed, rural population.

SELECTION CRITERIA: ASSESSING NEEDS, GAPS, AND BARRIERS

Exemplary Assessing Needs, Gaps, and Barriers sections met the following criteria (based on the Integrated HIV Prevention and Care Plan Guidance):

- Includes description of the process used to identify HIV prevention and service needs of those at risk and PLWH
- Demonstrates engagement of those at risk and PLWH in planning
- Clear and robust description of service needs
- Clear and robust description of service gaps
- Clear and robust description of barriers (social, policy, health department, program, service provider, and client barriers).



Additional exemplary plan sections are available online:
www.targetHIV.org/exemplary-integrated-plans

SECTION I. D. ASSESSING NEEDS, GAPS, AND BARRIERS

a. Process to Identify HIV Prevention and Care Service Needs

Public Advisory Input and Planning Process

A guiding principle for New York State's continuum of services is that, to be most effective, program development must be informed by input from the community. This includes HIV service providers, consumers, advocates, community representatives, government agencies, and other involved parties. The AIDS Institute receives such input on an ongoing basis from a variety of groups, including the New York State AIDS Advisory Council (AAC) and the AAC ETE Subcommittee, the Interagency Task Force on AIDS, expert clinical committees convened by the AI Office of the Medical Director, consumer groups, advocacy organizations/groups, other ad hoc work groups and the HIV Advisory Body (HAB), which was recently formed through integration of the Prevention Planning Group (PPG) and the Statewide AIDS Services Delivery Consortium (SASDC). Input is also received from the Part A planning councils: the HIV Health and Human Services Planning Council of New York; and the Nassau-Suffolk HIV Health Services Planning Council.

New York State's plan to end the epidemic resulted from input received from a variety of stakeholders. A 64-member ETE Task Force developed the *Blueprint* based on extensive (almost 300) recommendations received from the community via statewide stakeholder sessions, online forums, conference calls, and widely disseminated surveys. The *Blueprint* has been presented to planning bodies, advisory groups, other state and local agencies, and community representatives on an ongoing basis. Since its release on April 29, 2015, New York State has been working collaboratively with all partners to implement the recommendations included in the *Blueprint* and monitor their implementation. Further input continues, and the convening of several advisory groups to devise specific implementation strategies in support of the *Blueprint* recommendations is ongoing.

HIV Planning Bodies Workgroup (HPBW)

New York State, New York City and Long Island agreed to develop one Integrated HIV Prevention and Care Plan for 2017- 2021. The following planning bodies participated in this joint effort for New York State, New York City and Long Island:

- New York State HIV Advisory Body (NYS HAB)
- HIV Health and Human Services Planning Council of New York
- New York City HIV Planning Group
- Nassau-Suffolk HIV Health Services Planning Council
- The AIDS Advisory Council (AAC) and the AAC ETE Subcommittee were involved in the process due to the direct alignment of the plan contents with the ETE Blueprint

The HIV Planning Bodies Workgroup (HPBW) consisted of representatives from each of the planning bodies listed above. These representatives work in conjunction with New York State,

New York City, and Long Island staff to develop the Plan and identify HIV prevention and care service needs.

Integrated Plan Steering Committee

The Integrated Plan Steering Committee consisted of representatives from the NYSDOH, NYCDOHMH, Nassau County Department of Health, United Way of Long Island. These representatives met monthly to provide continuous input into the development of the plan. Steering Committee members also assisted in the coordination and development of the following sections:

- Epidemiologic Overview
- HIV Care Continuum
- Financial and Human Resources Inventory
- Assessing Needs, Gaps, and Barriers
- Data: Access, Sources and Systems

For a list of all members of both the HPBW and the Integrated Plan Steering Committee, please see Appendices B and C of this document.

Ending the Epidemic Regional Discussions

The AIDS Institute hosted twelve ETE regional discussions from August through November 2015. These meetings were held in each Ryan White Region to ensure that all stakeholders across New York State had equal and adequate opportunities to be included in the process. More than 800 New Yorkers participated in discussions on the implementation of the *Blueprint*.

Prior to each meeting, communications were sent to all HIV service organizations, funded providers, local planning bodies, local governments, consumer advisory committees, and others, including but not limited to representation of all Parts of the Ryan White program, to adequately inform all interested parties of the regional discussions. Each meeting had good representation and dialogue. In addition to discussing the service gaps and needs, key areas of The ETE *Blueprint* were discussed. This included: identifying persons with HIV who remain undiagnosed and linking them to health care, linking and retaining persons diagnosed with HIV in health care to maximize viral suppression so they remain healthy and prevent further transmission, facilitating access to PrEP for persons who engage in high risk behaviors to keep them HIV negative, and addressing social and structural barriers, such as access to housing, PWID prevention and care needs, LGBTQ health, housing and human rights, and increased opportunities for employment.

PWH, providers, clinicians, local government officials, community leaders, and members of federally recognized American Indian tribes participated in these discussions. At regional meetings, participants received updated information about HIV/AIDS in each region/borough; provided input on identified service gaps in each region/borough; participated in regional/borough discussions about ETE and the HIV Care Continuum; and engaged in detailed

discussions regarding the needs and gaps within their regions.

Local officials, including commissioners of health, mayors, and borough presidents, were involved in many of the discussions; these leaders have either developed or maintained involvement in local ETE implementation efforts. Continued community discussion and action planning play a valuable role in engaging partners statewide in the needs assessment process and in the implementation of ETE efforts.

In particular, the ETE Regional Discussions enabled partners to identify positive and sustainable actions addressing the needs and gaps specific to each region. Summaries and action reports informed the Statewide Coordinated Statement of Need/Needs Assessment, especially with regard to service needs, gaps, and barriers to HIV prevention and care services. These reports have also helped inform the goals, objectives, strategies, activities, and resources for section II of this document, the Integrated HIV Prevention and Care Plan.

In addition, a range of stakeholders participate in a variety of forums on specific topics, including but not limited to the aging of persons with HIV; the HIV testing law and regulations; prevention of perinatal HIV; social media and HIV and STIs; health equity for African American populations; health equity for Hispanic/Latino populations; and opioid overdose prevention.

Ending the Epidemic Statewide Community Call

A statewide community call opportunity was also provided, as a result of feedback received from the community. This call provided an opportunity for individuals to contribute to both the implementation of the ETE *Blueprint* as well as to the identification of HIV prevention and care service needs for inclusion in this Plan. The 90-minute call was held in April 2016 and dial-in information was widely shared. Nearly 200 individuals participated in the call from all regions of New York State.

Document Request and Review Process

The AIDS Institute distributed a request for data input documents, initiated by the NYSDOH, the NYCDOHMH, and Nassau County, to NY Part A EMAs and Planning Council members, Part B grantees, Part C and D grantees, SPNS grantees, AETC representatives, dental reimbursement program providers, persons living with HIV/AIDS, health and human service providers holding contracts with the AIDS Institute, Medicaid providers, local health units and other governmental agencies, AIDS Institute staff, advocates, and other interested parties. More than 150 source documents were received. These documents are listed and briefly described in the Appendices. The documents varied in content and format.

The information gathered has been organized and summarized in the respective sections of this document. The Plan is developed almost in total from the input received at the regional forums, the source documents listed in the Appendix, and other sources noted. It is not footnoted, but specific references to documents are indicated when appropriate.

b. and c. HIV Prevention and Care Service Needs and Gaps

The information in Section I.D.b., c., and d. is based on input from the ETE regional meetings, the ETE statewide community call, the HAB and AAC Subcommittees, the HPBW, as well as through the full planning bodies, along with needs assessment documents provided in response to the call for documents for this Plan. Needs and gaps are most often discussed simultaneously and are, therefore, described in one section.

Summary of Key Needs Identified by Regional HIV Planning Bodies

Identified Need	NYC						Nassau-Suffolk	Hudson Valley	Northeast	Central	Finger Lakes	Western
	Upper Manhattan	Lower Manhattan	Queens	Staten Island	Brooklyn	Bronx						
Expanded PrEP/PEP/nPEP access	✓	✓	✓	✓	✓	✓	✓	✓			✓	✓
Housing	✓		✓		✓	✓	✓	✓	✓	✓		✓
Food security	✓	✓	✓			✓	✓		✓			✓
Routine testing outreach and access	✓		✓	✓	✓	✓	✓	✓				
Transportation	✓	✓	✓			✓	✓	✓	✓	✓		
LGBTQ prevention and care, with a focus on transgender individuals	✓	✓	✓		✓	✓	✓	✓			✓	
Mental health services	✓	✓	✓			✓	✓	✓	✓	✓	✓	
Opioid use, HCV, STI, and HIV links	✓				✓	✓	✓			✓		✓
Syringe exchange	✓								✓			
Sexual health education	✓	✓	✓	✓	✓	✓	✓	✓	✓			
Linguistically, culturally appropriate materials and services	✓	✓	✓		✓	✓	✓				✓	
Rural access to testing, prevention, and care services									✓	✓		✓

Identified Need	NYC						Nassau-Suffolk	Hudson Valley	Northeast	Central	Finger Lakes	Western
	Upper Manhattan	Lower Manhattan	Queens	Staten Island	Brooklyn	Bronx						
Data sharing platforms			✓		✓		✓					
Focus on young MSM of color	✓	✓	✓		✓	✓						
Adolescent testing, prevention, and care services	✓		✓		✓	✓		✓				
Services for individuals over 50		✓	✓			✓		✓				
Coordination of referrals and services	✓	✓	✓		✓	✓	✓					
Provider training, education, and cultural sensitivity	✓	✓	✓	✓	✓	✓	✓	✓				✓
Substance abuse treatment	✓				✓	✓	✓		✓	✓		

Statewide Summary

The most commonly identified HIV prevention and care service needs of persons at risk for HIV and PWH across NYS identified through the statewide community forums and a review of needs assessment documents submitted by the HPBW can be summarized in the following broad categories.

- Comprehensive health care, integration of primary care (for HIV, STDs, hepatitis, and other co-occurring conditions) and specialty care for all persons, including those who are uninsured or underinsured
- HIV prevention, health education, and clinical education to raise awareness, build skills, eliminate stigma and discrimination, improve consumer health literacy, ensure high-quality care and services, and prevent further transmission of HIV
- HIV prevention and care services for groups of individuals at risk for HIV infection, including young MSM of color, heterosexual women of color, transgender and gender non-conforming individuals, recent immigrants, undocumented individuals, and those for whom English is not a first language
- Outreach, education and training, and provision of PrEP services, with expansion of

services for all groups who engage in high risk behaviors

- Prevention and care services for those who are in poverty, those who are homeless, those with substance use and mental health issues, those who are adolescents, as well as those in underserved and rural areas of the state
- Availability and cost of transportation and housing
- Accessibility of mental health services and dental care
- Case management and supportive services that enable linkage to and retention in care as well as compliance with medication regimens, including but not limited to food/nutrition services, legal assistance, entitlements/benefits assistance, family support, peer education and support, and translation and interpretation
- Increased access to Hepatitis C services
- Increased access to harm reduction services
- Linguistically and culturally competent services in all settings
- Targeted outreach to provide HIV testing, case finding, linkage to care, and prevention
- Service delivery models that meet patient needs, such as evening and weekend hours, co-located services, neighborhood service sites, and improved service integration and coordination
- Accessibility of drug treatment programs/services
- Opportunities for consumers to share information and exchange support
- Interventions that address stigma
- Education for consumers and providers on the changing health care environment as a result of Medicaid redesign and health care reform

While not an exhaustive list, the challenges and emerging issues discussed in this section are crosscutting and must be considered in the planning process. Examples include:

- Sexual transmission of HIV and other diseases
- Integration of HIV, STDs, and hepatitis prevention and care
- New infections among young MSM of color
- Aging of the HIV epidemic
- Residual mother-to-child transmission of HIV
- Hepatitis C and STD co-morbidities
- Late/concurrent diagnosis and entry into care
- Workforce development issues
- Difficulty associated with retention in care
- Meaningful provider participation in Medicaid reform and DSRIP

ETE Task Force members discussed the importance of addressing complex and intersecting health and social conditions and reducing health disparities, particularly among New York's low-income and most vulnerable and marginalized residents. Many current implementation efforts seek to diminish barriers to care and treatment so that ETE achievements leave no one population behind.

The ETE *Blueprint* addressed the fact that new HIV infections do not happen in isolation, but rather come tied to numerous factors. The following are a number of these factors, identified via input from ETE Task Force members and through the review of scientific evidence:

- Health care issues, including access to medications, condoms, and clean syringes; insurance coverage; the need for increased cultural competency training for both medical and nonmedical providers; access to health support (e.g., peer navigators, medication adherence support); access to HIV/STI screening; access to confidential services; importance of moving from testing to linkage to care; access to health and sexual health education.
- Poverty, including housing issues, food insecurity, unemployment/underemployment.
- Survival sex work and inequality, which often encompass incarceration, undocumented status, stigmatization, disempowerment, discrimination, penalization of condom carriers, domestic violence, unfair drug laws.
- Mental health problems, such as depression, substance abuse, impulsivity, fatalism, disengagement, religious guilt, cognitive problems, history of traumatic experiences.
- Geographic disadvantages, including engagement in risk behavior in areas (or in social networks) with high HIV prevalence and lack of treatment options for co-morbidities that make HIV acquisition more likely.

In many cases, these factors overlap; however, certain populations are more affected by contextual factors and experience higher rates of associated health disparities. These include: (1) MSM, especially Black and Hispanic/Latino MSM; (2) all transgender people; (3) women of color; (4) persons who inject drugs; and (5) sero-discordant couples, in which one partner is HIV-positive and the other is HIV-negative.

Prevention Needs

There is universal support for enhanced prevention and additional harm reduction efforts. The following comments/recommendations were commonly raised:

- Increased and more effective prevention messaging and programming is needed, specifically targeted at priority populations.
- Cultural and linguistic competence is extremely important.
- Enhanced and expanded PrEP and nPEP information, outreach, and services are needed.
- Increased prevention messaging in schools and enforcement of existing mandates is required.
- Condoms should be more easily accessible.
- Enhanced partner notification and counseling services are needed.

- A wellness approach to prevention should be taken.
- Despite promising research showing that use of PrEP with risk counseling can reduce transmission, there are barriers to expanding this approach.
- Expanded use of CDC’s Diffusion of Effective Behavior Interventions (DEBIs) and/or homegrown versions was recommended.
- Additional expanded syringe access programs (ESAPs) and syringe exchange programs (SEPs) are needed, particularly in upstate areas and Long Island.
- The availability of buprenorphine should be expanded.
- There should be an increased use of peer harm reduction and prevention approaches.

STD Clinics as Hubs of HIV Care and Prevention

The *Blueprint* introduces the idea of “STD clinics...as one-stop-shops.” Supporting this *Blueprint* recommendation is an ETE Task Force committee recommendation that envisioned STD clinics becoming “HIV One-Stop” centers and “hubs of care.” Since the writing of The *Blueprint*, NYCDOHMH has secured funding for implementing the major features of STD clinics as HIV hubs of care and prevention in its network of eight STD clinics, as envisioned by the ETE Task Force. It was recommended that efforts should be made to address the feasibility of adapting this model for STD clinics outside of New York City.

As recommended, an STD clinic that is a one-stop HIV hub of care and prevention will offer:

- HIV testing to every visitor, unless that visitor is known to be living with HIV
- Immediate treatment to everyone found to have HIV infection—ideally through starter packs of ART
- A full 28-day course of PEP after a suspected exposure to HIV, and the evaluation of every PEP patient as a candidate for PrEP
- Starter packs of PrEP for those deemed at risk of repeated exposure to HIV
- Navigation to long-term affordable health care for everyone who needs and accepts it, whether that person tests HIV-positive or HIV-negative and at risk
- Navigation to: (a) mental health services; (b) contraceptive and reproductive health services; (c) help with substance use, as needed; navigation to be provided by Certified Peer Workers and/or Community Health Worker staff, either directly by the STD Hub or through a subcontract with the community

The ETE Task Force advocated for the model of STD clinics as hubs of HIV care and prevention to be implemented outside of New York City (as well as to testing settings other than STD clinics). It was further recommended that NYSDOH consider writing the most important features of the hub of care and prevention model into a set of minimum standards for jurisdictions to fulfill their mandate to provide STD services to their residents. It was also recommended that, where governmental and non-governmental drop-in centers and hub-type programs are in place, New York State encourage and financially support the co-location of food and other services, both to entice patients and to make it easier for them to obtain the supports they need. New York State should also explore whether DSRIP and Value-Based

Payment (VBP) structures include incentives to screen for STDs, including the use of point of care STD testing and other tools that support swift diagnosis and treatment.

Third-Party Billing in STD Centers

While allowing STD testing and treatment centers to bill third-party payers is an innovative and cost-effective strategy to stretch scarce testing resources across the state, it is imperative to avoid the unintended consequence of the complexity of instituting billing being a disincentive for providing testing and treatment services.

In theory, billing for STD testing and treatment should be straightforward; the ACA and the expansion of Medicaid have provided opportunities for New Yorkers to access affordable insurance coverage. There is, however, a marked difference between individuals presenting with insurance for routine medical care and those seeking STD testing and treatment services. Strong stigma, along with patient concerns and expectations about confidentiality, often leads individuals entering STD clinics either to deny having active insurance or to refuse to present insurance documentation.

Young People's Right to Consent and Right to Confidentiality

Individuals from all regions recognize that young people encounter issues regarding disclosure of their health information -- through Explanation of Benefits (EOBs), for example. Ensuring young people's right to the provision of confidential sexual health care services is essential to achieving ETE goals.

Hepatitis C Virus (HCV)

People with HCV have difficulty accessing the necessary HCV-related health care services. In addition, many individuals with HCV present with co-morbidities, such as mental health disorders and substance abuse, circumstances that further negatively affect their engagement with and retention in care. HCV infection is more serious in an individual with HIV/AIDS than in an individual who is not HIV-positive, leading to liver damage more quickly and potentially affecting treatment for HIV/AIDS.

The following HCV-related statements of need emerged across the regions:

- A "one-stop shop" integrated model is needed, as it maximizes clients' access to services, improves coordination of comprehensive care, and reduces missed opportunities to address the multiple health care needs of patients.
- HIV, STD, and HCV testing should be integrated.
- Enhanced education and resources directed at the early identification, care, and treatment of persons with HCV are needed.
- More HCV screenings should be conducted in jails and prisons.
- Social media could be used for people with HCV to share stories and information.

- There is a need for increased access to treatment for those with hepatitis C/HIV co-infection

Substance Use

In the late 1980s and early 1990s, the HIV epidemic in NYS was driven by substance use. In 1992, the Commissioner of Health was given regulatory authority to approve syringe exchange programs (SEPs). In 2000, the Expanded Syringe Access Program (ESAP) was established. This program augmented harm-reduction efforts for PWID by enabling health care professionals to provide syringes and pharmacies to sell them, and by establishing safe sharps disposal programs throughout New York State. Syringe access in New York State has yielded impressive results. As a result, the proportion of PWID (including those with dual PWID/MSM risk) among newly diagnosed cases has dropped dramatically. Substance users are now more likely to acquire HIV through sexual transmission than through needle sharing. Syringe access also helps control the spread of hepatitis C.

Substance abuse, however, remains a major issue in New York State. The Office of Alcoholism and Substance Abuse Services (OASAS) estimated there are as many as 170,000 PWID in New York State, only 41,000 of whom are enrolled in OASAS treatment programs. In the Long Island region, representatives spoke of the increase in opiate use, which is reaching epidemic proportions. Participants in the community forums noted an alarming increase in drug use among adolescents.

Native Americans and HIV, STDs, and HCV in New York State

The American Indian Community House (AICH) offers a range of HIV, STD, and hepatitis C prevention services at the individual, group, and community levels. The AICH HIV/AIDS program provides referrals and links individuals who engage in high risk behaviors to testing and screening for HIV, STDs, and hepatitis C. The program also offers support services through Native American cultural activities to help individuals reduce their risk and remain in care; it promotes traditional healthy lifestyles as well as healing from historical and intergenerational trauma. Services are provided through four program sites in New York City, Akwesasne, Syracuse, and Buffalo.

According to information provided by the AICH, data on Native Americans with HIV/AIDS, STDs, and HCV (Hepatitis C) appear to be incomplete and inaccurate. Native American HIV/AIDS data are unidentified and misidentified for a number of reasons:

- A perceived lack of confidentiality within small Native American communities; many Native Americans are reluctant to seek testing at nation/tribal health clinics.
- Mistrust of the government and non-Native American providers, and because of a lack of culturally competent services, many Native Americans are reluctant to seek testing outside of the Native American community.
- Some Native Americans may be reluctant to identify themselves as Native American when they seek services due to stigma and stereotypes.

- Some Native Americans are misidentified as being of another racial/ethnic group.
- Many Native Americans previously identified, likely including those who are enrolled and unenrolled in their nations/tribes, have been reclassified as “multi-race.”
- Native Americans constitute roughly 1% of the population. Existing numbers are relatively small and do not generate statistically significant data for comparison with that of other racial/ethnic groups.

Despite all of these issues, the data are nonetheless strongly suggestive, and often support anecdotal observation by Native American providers. Nationally, AI/AN have the second-highest rates of chlamydia, gonorrhea, and syphilis among all racial/ethnic groups. STIs increase the susceptibility to HIV infection.

Native American HIV, STD, and HCV-related needs in New York State include the following:

- Native Americans are reluctant to seek testing and screening for HIV, STDs, and HCV. They seek testing later than other racial/ethnic populations.
- Viral suppression among PWDHI is low among Native Americans, suggesting that retention of Native Americans in care is an issue.
- Native Americans may be largely unaware of PrEP; Native Americans who engage in high risk behaviors may not seek PrEP; and there is a lack of materials on PrEP specifically tailored to the Native American community.
- Native Americans at high risk need support in healing from trauma as part of reducing risk behaviors.

Regional Themes

The need for increased access to the following categories of care was most often cited by the regions, including:

- Primary care
- HIV specialty care
- Mental health services
- Substance abuse services
- Dental services

The need for increased coordination of the complex care needed by PWH was raised in some regions. Suggestions offered to improve coordination of care included:

- Enhancement of case management services
- Increase in the availability of “one-stop shopping” health care models and community health centers
- Better integration and communication among providers
- Medicaid redesign may help ensure that PWH and other patients are enrolled in programs that coordinate care

Concerns regarding the following health matters were raised in various regions of the state:

- Pain management and alternative care
- Dental care
- Aging practitioners
- Increasing complexity of care
- Mental health services
- Substance abuse services
- Care of aging PWH
- Immigrant health care and care for undocumented individuals
- Health care for children, youth, and adolescents
- Care of individuals newly diagnosed
- Prisoner and releasee health care
- Care for the “bookends” of the epidemic (the young and the old)
- Hepatitis C co-infection care
- Care for transgender and gender non-conforming individuals
- Care for non-English speakers and those from diverse cultural and ethnic backgrounds

HIV and STDs

Ensuring STD screening in HIV primary care is essential. At regular intervals, HIV primary-care providers should offer recommended STD screening tests to HIV-positive individuals and to at-risk HIV-negative individuals, including those on PrEP, as per New York State guidelines. To promote STD testing, chart reviews of major HIV primary-care providers should be conducted. This process would allow baseline STD testing among persons engaged in HIV primary care to be quantified, and it would facilitate surveys among providers to assess barriers to STD screening and treatment. As part of provider training, enhanced risk-assessment tools should be developed. In order to respond appropriately to positive tests, there should be financial and other support for single-dose point-of-care treatment whenever possible. Furthermore, billing toolkits should be developed to enhance reimbursement for covered preventive services, including STD screening, appropriate vaccinations, and sexual behavior counseling. Finally, options should be explored to ensure treatment for uninsured and underinsured persons, regardless of setting. In New York State, more than two-thirds of STDs are diagnosed outside the public-health STD clinic setting. Identifying and enabling STD treatment providers to initiate PrEP, nPEP, and ARV treatment is integral to meeting New York’s ETE goals.

Across the state, community representatives identified STI/STD needs including the following:

- People with STDs need to be linked to care, and HIV and STD services need to be integrated in the community.
- The integration of HIV, STD, and HCV testing is viewed as critical and must include counseling, risk reduction, and harm and risk reduction supplies. STD screening needs to be expanded, especially in nontraditional settings. Rapid testing is needed

for STDs, particularly for youth.

- There is a need to monitor how the uptake of PrEP is affecting STD rates in as close to real time as possible.

Some New York State local health department (LHD) STD clinic programs face challenges in offering STD services proportionate to their communities' needs. Rural county health departments are more likely than suburban and urban counties to contract with outside agencies to provide the STD clinical services required by public health law. Rural counties that offer direct services, and even those with contract providers, must frequently limit the available hours of operations, a trend less often seen in suburban and urban counties. In some cases, clinics are open for just one to two hours a week in the morning, or a couple of hours every other week.

Syringe exchange programs and substance use treatment

Participants in the community forums, regional documents, and other advisory groups all note the need for additional syringe exchange programs throughout the State, particularly upstate. Participants expressed concern that insurance does not adequately cover substance use treatment. There is a shortage of substance use treatment slots, particularly in areas outside of New York City. There is a continuing need for education and prevention efforts targeted to substance users.

Housing

Inadequate access to safe, stable, and affordable housing for PWH was identified as a significant issue in every region. Homelessness and housing instability increase the cost and complexity of care. Many of these costs can, however, be averted through investments in supportive services that stabilize the housing of PWH.

Transportation

The efforts made by the AIDS Institute to address transportation needs were noted. However, areas remain where limited access to reliable transportation discourages people from going to the doctor or pursuing other needed services. The transportation infrastructure in rural and suburban areas needs improvement. Staten Island and parts of Nassau and Suffolk Counties as well as regions of upstate New York also have limited access to transportation.

Issues identified regarding transportation included:

- Burdensome administrative process for consumers seeking to secure bus passes
- The need for increased reimbursement for transportation for travel to support groups, non-medical services, and meetings
- Needed improvement to medical transportation services
- Limited hours of operation for public transportation systems in some cities

Case management

There was widespread support for regional case management programs. Their value in assisting with care coordination, case referral, adherence to treatment, navigation of the health care system, health care coverage plans, support services systems, and working with the community was praised. There were, however, a number of suggestions to improve case management programs:

- Additional case managers are needed as caseloads are too high. Travel time consumes much of the day in rural and remote areas.
- Multilingual and culturally competent case management is necessary to reach the diverse communities living in New York State.
- Case management services are needed in shelters and supportive housing.
- Improved case management tailored to the needs of aging PWH and the mentally ill is needed.
- Training should be provided to consumers on how to access and effectively use case management services.
- Training should be provided to case managers on new, current, and discontinued services, as well as on the stigma associated with HIV/AIDS, STDs, and mental illness.

Nutrition Support

Several regions identified the importance of nutritional support for PWH. Food insecurity is a source of chronic stress that has consequences for physical health, as well as for mental health and for adherence to medical treatments. PWH who are food-insecure score lower on standardized measures of physical health functioning, mental health functioning, and quality of life. Research has shown that food insecurity is associated with increased morbidity and mortality among HIV-infected persons. During the community forums, the importance of coverage for nutritional supplements was noted.

Employment

Research findings reflect a positive relationship for PWH between employment and employment services, and access to care, treatment adherence, decreases in viral load, improved physical and behavioral health, and reduction of health risk behavior.

The need to expand access to employment and employment services for people living with HIV/AIDS to improve HIV health and prevention outcomes was raised in several regions, especially when discussing the needs of key populations. The need for job opportunities, employment counseling, and readiness training were specifically mentioned. One of the recurring issues raised was the potential loss of covered services and benefits if a PWH returns to work.

Legal Services

Several regions identified the need for enhanced legal services to help PWH with civil legal problems, including protection from abusive relationships; access to safe and habitable housing and necessary health care; tenant-landlord issues; consumer debt issues; pursuit of disability payments, public assistance, and health insurance benefits; and family law issues such as child support, custody actions, and relief from financial exploitation. The need for legal assistance with wills, health care proxies, and other advance directives was also raised.

Other Needs for Key Populations

Several regions advocated for the increased availability of PrEP for undocumented persons, and for additional PrEP advertising—in both Spanish and English—geared toward African American and Hispanic/Latino communities.

Regions recommended expanded HIV testing; the redesign of the screening questionnaire so it captures more HIV-positive results and increases the opportunity for PrEP to be discussed as an option; expanded accessibility to PrEP for all populations, not just those at high risk, and accessibility of PrEP for youth; PrEP counseling for sero-discordant couples; the streamlining of PrEP insurance paperwork; more provocative advertisements across media platforms to encourage positive behaviors, reduce stigma, and inform people about PrEP; provision of integrated health services for patients (e.g., STD testing in conjunction with HIV screening); education of individuals on PrEP about STDs; and increased use of local statistics regarding new infections.

Participants noted that there are still barriers to routinizing HIV testing. For instance, youth might be reluctant to get tested for HIV because they cannot receive care without parental consent. Participants called for partnerships between HIV and non-HIV service organizations, increased involvement of faith-based organizations and other key local representatives in ETE work and conversations, and collaboration between CBOs and law enforcement. Some advised providing incentives to encourage undocumented individuals to receive testing.

In addressing specific populations, participants cited the need for prevention and care services particularly for young MSM of color; the importance of reaching young people and educating parents; and the need to engage the transgender and gender non-conforming communities, specifically transgender men of color.

Participants raised the issue that substance users often cannot access care due to insurance issues. Despite the success of opioid overdose prevention training, this much-needed service is underfunded.

Education

Recommendations relating to consumer education include:

- Education geared to each age demographic and culture of consumers
- Enhanced, targeted sexual health education
- Access to broad-based education to address literacy and general education gaps
- Enhanced training on Hepatitis C
- County health departments should work with community organizations to increase availability of STD education
- Enhanced peer education in special populations
- Education on health system navigation to assist consumers regarding informed decisions and retention in care
- Education that counters the notion that “HIV/AIDS is over” or that medical therapy eliminates the importance of prevention
- Education regarding the transition to Medicaid managed care and Health Homes

Each region identified needs and gaps in educational opportunities regarding HIV/AIDS and STDs. In particular, the following recommendations were identified:

- Institution of school curricula that support comprehensive, age-appropriate sexual health education, including risk identification and prevention practices for STDs and HIV/AIDS
- Training regarding HIV/AIDS for school faculty and administrators
- Establishment of HIV advisory committees in schools
- Enforcement of state education mandates

Region-Specific Issues

This summary describes statewide service needs in each region of New York State: New York City (NY EMA) and its boroughs, the Nassau/Suffolk EMA (N-S EMA), Northeastern Region, Central New York Region, Finger Lakes Region, Western New York Region, and Hudson Valley Region. As noted in the beginning of this section, the information is based on input from regional meetings, community calls, planning bodies, and needs assessment documents provided in response to the call for documents for this Plan.

New York EMA, City-wide. As reported by the New York City EMA, New York City has a large population of PWH, and there are continuing shifts within the epidemic. Multiple factors contribute to HIV transmission in a city as large and diverse as New York City, and disparities in rates of diagnosis persist. Prevention of HIV transmission is, therefore, a substantial and complicated undertaking. Fortunately, New York City is one of the best-equipped cities to address the HIV/AIDS epidemic. It has large networks of committed professionals, networks of infected and affected persons, an established community

planning process, and the world's premier infrastructure for HIV-related medical treatment and care.

NYCDOHMH is a key leader and partner in New York State's ending the epidemic efforts. Key objectives for New York City residents are to know their HIV serostatus, prevent secondary transmission, and obtain the care and services they need to maintain their health and quality of life. To achieve these goals, continued normalization and expansion of opportunities for voluntary HIV testing are needed, as is ongoing expansion and refinement of proven, scalable, culturally sensitive, and cost-effective HIV prevention interventions for the appropriate priority populations and neighborhoods.

New York City offers many settings for HIV diagnosis and expert care, as well as an extensive institutional support system for persons with HIV. For persons confirmed positive, providers must arrange an appointment for medical care. The city's Designated AIDS Centers (DACs), which are distributed throughout the five boroughs, are accessible 24 hours a day by public transportation. Medical and prescription drug benefits are designed to ensure that no person goes without care or ART because of a lack of resources. Case management, housing, and nutritional benefits are also available. DACs and large medical facilities have the administrative capacity to reduce many traditional barriers to care by arranging entitlements and ensuring access to support services. Most private physicians treating patients with HIV also have institutional relationships with hospitals offering these services.

The NYCDOHMH is committed to ensuring that all persons are routinely offered voluntary HIV testing and that all persons newly diagnosed with HIV receive post-test counseling; assistance with partner notification; and prompt, proactive linkage to medical care. The department is equally committed to assisting diagnostic providers—from individual physicians to large medical institutions and community-based organizations—to provide these services to patients, their contacts, and others at risk.

The benefits of timely diagnosis of HIV can be fully realized if diagnosis is followed by prompt initiation of HIV-related medical care. Care provides opportunities for counseling, initiation of treatment, referral to supportive social and medical services, and prevention of ongoing transmission. It is important for all persons newly diagnosed with HIV, as well as persons living with a prevalent infection, to initiate and remain in care.

PWH in the NY EMA overall have high levels of prompt linkage to and engagement in HIV primary care; however, those who are homeless or actively use drugs are more likely to delay entry into care. While evidence indicates that prompt linkage to medical care by staff at the testing site decreases the likelihood of delayed entry into care, higher levels of engagement in HIV primary care does not necessarily translate into improved clinical outcomes for PWH. People of color have lower rates of viral suppression than whites, in spite of consistently higher rates of retention in care. The gap between engagement in care and viral load suppression could partially be due to difficulties associated with adherence to antiretroviral therapy as a result of other unmet health and social needs. The need for supportive services, particularly

food and nutritional assistance, housing assistance, and mental health services, is high among PWH in the New York EMA. Existing supportive services may be underutilized and/or less accessible to certain populations, such as LGBTQ youth and MSM, as well as the homeless and/or unstably housed. Underutilization may be due to a variety of factors, including accessibility and availability of services, competing priorities, and the perceived value or stigma associated with such services.

Needs of Specific Populations in New York City

The New York EMA has large subpopulations of individuals who by life circumstances are at risk for HIV infection, progression to AIDS, and lack of engagement and retention in care. Among these groups, the specific populations of particular concern are the following:

Heterosexual Black and Latina Women in High-Prevalence Neighborhoods

Data document the burden of HIV for Black and Latina women. Given their ability to influence social norms, provide support, and exert influence across a community, social networks may be particularly apt targets for interventions. In fact, social network approaches have been successful among other communities at risk for HIV infection (e.g., PWID) and may be adaptable to this population as well.

Persons Admitted to the NYC Correctional System

Inmates have an elevated HIV prevalence relative to the general population, a trend that renders correctional facilities unique sites for HIV diagnosis and initiation of care.

Persons Using the NYC Shelter System

A previous analysis of both HIV data and statistics from the Department of Homeless Services, not subsequently repeated, revealed a disproportionate burden of HIV among homeless persons.

Hard-to-Reach PWID

Despite the significant, documented impact of syringe services on the HIV epidemic in New York City, geographic and racial/ethnic disparities in ongoing HIV transmission among PWID and their sex partners persist. These ongoing gaps may be due to limitations in syringe service coverage as well as difficulties engaging some PWID who are unwilling or unable to access syringes from existing sources. Additionally, with the success of syringe services and the trend toward non-injectable narcotics, it is important to expand the current concept of HIV risk and drug use beyond injection alone to incorporate the sexual risk-taking behaviors associated with various types of drug use. Reaching highly marginalized groups of PWID is an important priority. Innovative programs to promote peer-delivered harm reduction services and to provide social support to hard-to-reach PWID have been identified as priority activities.

Recently Arrived Immigrants and Migrants from Populations at High Risk for HIV

New York City has historically attracted great numbers of immigrants and migrants, including MSM and transgender and gender non-conforming persons. As individuals encounter new social environments and navigate the challenges of an unfamiliar city, some may be at increased risk for HIV infection. Providing tailored HIV prevention and social supportive services to this population is important to address their vulnerabilities.

People Who Exchange Sex for Money or Nonmonetary Items and Their Partners

There are limited data about the burden of HIV among people who exchange sex for money or nonmonetary items in New York City, but the multiple links between sex work and HIV vulnerability suggest that the prevalence may be high. People who exchange sex for money or nonmonetary items, who may identify as male, female, and/or transgender or gender non-conforming, are at risk for HIV infection because of the number of partners and possible exposure to HIV. People who exchange sex for money or nonmonetary items are likely to experience violence and coercive sex, both of which increase their risk of HIV acquisition or transmission. Prevention is paramount to protect both these individuals as well as their partners, who might in turn transmit HIV to others. Innovative, targeted HIV prevention programs may play an important role in reducing STD incidence and prevalence among people who exchange sex for money or nonmonetary items and their clients.

New York EMA, Upper Manhattan. To meet the needs of PWH and individuals at risk for acquiring HIV, participants advised advocating for routine testing among all New Yorkers to facilitate linkage to care, and for use of PrEP among populations who engage in high risk behaviors to prevent transmission. In particular, participants recommended disseminating information about the simplicity of HIV testing to youth, and disseminating information about the efficacy of PrEP to African American and Hispanic/Latino individuals in Harlem. To optimize care and resource use, participants suggested performing a cost-benefit analysis of universal testing vs. targeted testing to determine which is more effective in capturing persons with HIV who are unaware of their status.

New York EMA, Lower Manhattan. Participants from this region offered recommendations that focused on the training of care providers. First, they noted the need to improve provider training programs, such as medical schools and training programs for physician assistants, nurse practitioners, nurses, and home health aides. They also recommended developing an HIV Care Continuum dashboard for medical as well as non-medical providers. Similarly, they suggested creating a network including traditional as well as nontraditional stakeholders. Then, to ensure a high quality of care among all providers, they advised improving the dissemination of prevention and care best practices. Finally, participants noted the need to focus prevention efforts on LGBTQ youth of color, particularly those individuals who engage in high risk behaviors who do not know their status.

New York EMA, Queens. The borough of Queens has a particularly diverse population. Many residents were born outside of the United States, and hundreds of cultures are represented. The challenge of reaching this linguistically and culturally diverse population to provide information about HIV, STDs, and HCV is considerable. Participants noted the need for a “universal language” that would enable all people, notwithstanding their education or socioeconomic background, to engage in discussions about sexual health. Participants also stated that social determinants of health—including housing and consistent employment—also present challenges to maintaining quality health care. To address these, participants recommended instituting provisions to secure social and structural services that would facilitate retention in care and maximize viral suppression among individuals diagnosed as HIV-positive. Participants also focused on the delivery of health care. They emphasized the need for primary-care physicians to integrate supportive services into their practices. They also advised that non-medical providers should receive adequate training to guarantee quality care delivery at all points of entry.

Participants suggested strategies for engaging individuals at higher risk for HIV infection. In particular, they noted the need for Parent-Teacher Association discussions geared toward facilitating open parent-to-child dialog on sexual health education. They also noted the need for greater emphasis on the sexual health of older adults. Participants also advised that African American and Hispanic/Latino MSM ages 18–30 need additional supportive services—such as educational, housing, and financial support—to achieve viral load suppression and other positive health outcomes. To remove a key barrier to care among MSM and transgender and gender non-conforming persons, participants noted the need to address possible inequities within the legal system. Finally, participants emphasized the importance of HIV prevention. To that end, they advocated for the increased availability of PrEP for undocumented persons, and for additional PrEP advertising—in both Spanish and English—geared toward African American and Hispanic/Latino communities in the Jamaica and Flushing Queens neighborhoods.

New York EMA, Staten Island. Participants from this region emphasized the importance of improving education and care options for young people. In particular, they highlighted the need for borough schools to address sexual health education—with a holistic curriculum focusing on the entire individual—and for the legislature to pass a comprehensive bill allowing minors to make decisions regarding their sexual health care. They also noted the importance of HIV testing and emphasized the need for expanded HIV testing among those engaging in high risk behaviors. In addition, they advised that medical and nursing associations should work to normalize HIV testing, also noting that physicians would benefit from additional training in effective methods of offering HIV tests to their patients. Finally, participants emphasized the importance of prevention and called for greater access to PrEP as well as additional support from the NYCDOHMH to identify PrEP/PEP providers and to increase PrEP/PEP education on Staten Island.

New York EMA, Brooklyn. Brooklyn is the most populous of the boroughs. In addition to expanded HIV testing, participants emphasized the importance of linking those at risk and not virally suppressed to quality health care. In order to retain individuals in care, participants

noted the need for skilled, knowledgeable, and culturally competent staff interacting with PWH; an easily accessible and up-to-date HIV/AIDS resource directory; increased client tracing among agencies; testing in nontraditional venues; coordination among HIV supportive services agencies; collaboration among CBOs to provide services for MSM with STDs; LGBTQ-affirming, safe spaces at provider locations; acknowledgment of the health impact of socioeconomic factors; provision of legal services to ensure that persons who are at-risk maintain housing; negotiation with diagnostic and pharmaceutical companies for discounted test and medication prices; recommendation of the one-pill-a-day regimen for PLWDHI to improve treatment adherence and viral suppression; importance of providing patients with reminders to take medication; need for inter-agency evaluative tools to assess the efficacy of health care providers; and the importance of addressing burnout among medical providers.

Participants also emphasized the importance of HIV prevention in the borough. They recommended expanded HIV testing; the redesign of the questionnaires that are used prior to testing to increase opportunities for PrEP to be discussed; expanded access to PrEP for all populations, not just those determined to be at “high risk”, and a reduction in the age of consent for PrEP; PrEP counseling for sero-discordant couples; the streamlining of PrEP insurance paperwork; more provocative advertisements across media platforms to encourage positive behaviors, reduce stigma, and inform people about PrEP; provision of integrated health services for patients (e.g., STD testing in conjunction with HIV screening); education of individuals on PrEP about STDs; and the increased use of local statistics regarding new infections.

New York EMA, Bronx. The Bronx is one of the poorest areas in the nation. Participants noted that there are still barriers to HIV testing, which should be routinized. For instance, youth can get tested for HIV, but they cannot receive care without parental consent. Participants also noted that the current level of funding some providers receive creates competition where collaboration should otherwise prevail. Similarly, they called for partnerships between HIV and non-HIV service organizations, the involvement of faith-based organizations and other key local representatives in ETE work and conversations, and collaboration between CBOs and law enforcement.

In addressing specific populations, participants cited the need for prevention and care services for young MSM of color; the importance of reaching young people and educating parents; the need to engage transgender and gender non-conforming individuals, and specifically transgender men of color; the need for a LGBTQ space in the Bronx; and the importance of soliciting input from young as well as older individuals who are HIV-positive. Participants also called for provider and political accountability in ensuring resources are available to the appropriate populations.

Finally, participants emphasized the importance of prevention. Noting that the designation “high risk” can be a barrier, they cautioned that everyone is at high risk. In addition, they expressed the need for increased marketing for, access to, and education about PrEP. They also called for HIV testing at high-traffic locations, such as the Department of Motor Vehicles, but

warned against focusing on such venues as dance clubs and bars, where people may not be open to being approached; they similarly noted the need for programs to offer services outside of regular business hours. Participants suggested offering incentives to individuals for learning/knowing their status.

New York EMA, Montefiore Medical Center, Bronx. Participants from Montefiore Medical Center, the academic medical center and University Hospital for the Albert Einstein College of Medicine, strongly emphasized the need for greater prevention efforts. In particular, they called for a PrEP Continuum of Care, with recommended intervention strategies at each step. Participants also recommended collecting and disseminating data on linkage of individuals who are HIV-negative who engage in high risk behaviors to PrEP via emergency room visits. Calling for a two-pronged adolescent PrEP initiative, they recommended both funding PrEP services and providing ongoing intervention to ensure retention. Montefiore's Adolescent AIDS Program currently has a PrEP pilot program underway. They expressed concern about the lack of implementation of HIV/AIDS and sex education, including pregnancy prevention information, in schools. Finally, participants identified the need for ongoing support for provider HIV assessment and training, including for oral PrEP and future prevention modalities; they also noted the importance of engaging primary-care providers as well as other health care professionals (e.g., urgent-care providers, emergency room providers, et al.).

Regional Spanish-Speaking Summit, New York City. Participants pointed to barriers affecting specific populations. An overall theme was the need for bilingual, bicultural providers who understand the needs of the community, as well as bilingual peer educators who are familiar with communities at risk. Participants similarly emphasized that agencies receiving funding to serve communities of color should ensure that they are also serving Hispanics/Latinos, and that agencies serving Hispanics/Latinos should target those who are primarily Spanish-speaking. In general, services should take into account national origin, years of residence in the United States, acculturation and assimilation, and level of English proficiency. There is also a need for better understanding of Hispanic/Latino communities living with HIV and at risk for HIV. For instance, social marketing campaigns need to reflect the community; messages should not just be direct translations of English-language campaigns. Participants recommended involving experienced community partners to develop meaningful campaigns in Spanish alongside those in English. Due to resource limitations, participants urged cooperation among organizations whenever possible.

Participants discussed service needs and barriers for Hispanics/Latinos of all ages. They noted that while HIV testing is broadly available, individuals over age 50 cannot always access it; moreover, because of stigma and ageism, physicians don't always discuss sex with patients over 50 years old. Older Hispanics/Latinos living with HIV need services for long-term survivors, while younger Hispanics/Latinos living with HIV tend to need services relating to mental health, depression, and loneliness.

In general, participants called for services to meet the mental health and substance use needs of Spanish speakers and communities at risk. The lack of mental health literacy, they noted, leads to less access and use of mental health providers.

Participants also noted the need for additional programs to help people disclose their HIV status—and in particular, for programs in Spanish geared toward substance users and women who are victims of domestic violence.

Noting the cultural role of “machismo,” participants emphasized the importance of educating immigrants about HIV transmission risks through sex as well as IV drug use. When targeting MSM, participants called for a better effort to connect with men who do not identify as MSM and with men who have sex with transgender women.

Participants emphasized the importance of strengthening outreach to transgender and gender non-conforming communities, particularly immigrants who have fewer available resources and services. Transgender women attending Hispanic/Latino LGBTQ clubs, participants noted, experience harassment by the police in certain areas of the city. They also called for support/educational groups, especially for young, gay, Hispanic/Latino men who predominantly speak Spanish. Participants emphasized the importance of offering complementary services, including ESL and GED classes, workforce development, resume writing workshops, and legal guidance (for issues such as police harassment, political asylum, and residency requirements). They called for the development of lists of providers and community-based organizations providing services in Spanish.

Turning to transmission prevention, participants called for an expansion of PrEP and nPEP services. They called for the provision of information on PrEP to medical providers; an increase in the number of Spanish-speaking PrEP and nPEP providers, particularly in areas of New York City with high concentrations of Hispanics/Latinos; the education of providers, particularly for those who may have their own prejudices about prescribing PrEP, and who serve Hispanics/Latinos without insurance; and strengthening procedures in emergency rooms and primary-care provider offices pertaining to the offering of PrEP and nPEP so Hispanics/Latinos without insurance may access both. Participants further noted the need for improved emergency room provider knowledge regarding nPEP. They emphasized the importance of providing patients with nPEP and addressing the experience of nPEP-seeking clients who are advised to return to the hospital in three months for an HIV test; utilizing rebate programs; and offering medication directly at the hospital (rather than providing a prescription to be filled at an outside pharmacy, which may be unaffordable for people at risk).

Nassau-Suffolk (N-S) EMA, EMA-wide. For PWH in the N-S EMA, participants noted that increased costs in medical services create burdens of stress and worry, particularly when they are faced with multifaceted issues of co-morbidities, poverty, unstable housing, and lack of health insurance.

As reported by the Nassau-Suffolk EMA, opportunistic infections, hepatitis C, hepatitis B, and STDs adversely affect the health and welfare of PWH; in particular, STDs such as syphilis, gonorrhea, and chlamydia require compliance with timely medical care and further tax the already immunosuppressed systems of PWH. Hepatitis C co-infection with HIV acts as a catalyst in developing co-morbidities such as liver disease and failure, liver cancer, and cognitive impairment.

Co-morbidities also further burden a public health system that is already working to achieve viral load suppression in the EMA. For instance, tuberculosis is more complex and expensive to treat in PWH than persons with TB alone. Furthermore, inconsistent treatment for HIV with any co-morbid disease such as HCV, STDs, or TB supports increased drug-resistant strains, thus increasing the cost of treatment.

Challenges from the infrastructure of the bi-county EMA are compounded by the long and narrow topography of Long Island, which makes transportation a defining need.

Faced with these obstacles, many PWH prioritize their basic survival needs. As a result, they may not be able to fully comply with their drug regimens. Medication regimens, when discontinued, place PWH at risk for resistant strains and more complex therapies once care is reinitiated.

Key needs for the N-S EMA are as follows:

- Improved access to mental health services for PWH
- Improved access to dental services for PWH
- Increased access to qualified hepatitis C providers for diagnostic services as well as treatment for patients co-infected with HIV and hepatitis C
- Expansion of syringe exchange services. There is currently only one syringe exchange program in Long Island providing peer delivered services in both Nassau and Suffolk; Increase the number of syringes that can be purchased without a prescription at pharmacies enrolled in the Expanded Syringe Access Program (ESAP) especially given the 2014/15 Indiana HIV Outbreak; Develop State legislation to decriminalize the possession of syringes and condoms
- Medically Assisted Treatment (MAT): Enhance the availability of buprenorphine to individuals with opioid use disorders by increasing the number of physicians prescribing buprenorphine
- Increased rapid HIV testing: A comprehensive program for pharmacies to offer walk-in, on-demand rapid HIV testing
- Clinically and culturally competent care for transgender and gender non-conforming individuals
- Linkage to care: Expansion of existing programs to link or re-link PWH to care
- Transportation: Funds for transportation to access primary care and other core medical and supportive services (given the limited and difficult-to-navigate mass-transit system in the N-S EMA)

Various subpopulations in the N-S EMA are particularly likely to be underrepresented in the system of care. Their increasing numbers reflect the disproportionate representation of PWH among individuals with adverse socioeconomic indicators, such as high levels of poverty. Rates of chronic illnesses, co-morbidities, and other medical disparities further complicate care for these subpopulations. The N-S EMA identified the following key subpopulations along with their service needs:

Adolescents/Teens

Subpopulations among this group include college-age youth, particularly young women ages 16–24; PWID having condomless sex and/or multiple partners; gang members; those who were sexually abused; young MSM, bisexual men, or experimenting men (ages 13–24). Services needed are health education/risk reduction, training in negotiation skills related to sex, and education on and access to PrEP.

Youth

This group includes adolescents (ages 13–19) and young adults (ages 20–29). The Youth Needs Assessment conducted in 2013–2014 was a poll of 104 PWH respondents and 14 youth respondents. The study identified three groups with growth in newly diagnosed HIV cases: MSM of color, IDUs, and foreign-born teenage mothers. In Nassau County, the epidemic is complicated and perhaps exacerbated by relatively low socioeconomic conditions, high rates of drug use (particularly crystal meth and prescription drugs), and ostracism and bullying based on sexual identity. Nassau County respondents reported high rates of suicidal thoughts (56%), problems coping with sexual identity (67%), and cutting or self-harm (61%).

Older Adults Ages 50+

Older adults may not be aware that they may be engaging in behaviors that put them at-risk for acquiring HIV. Services needed for older adults include health education/risk reduction and information related to safer sex.

Persons Who Inject Drugs

Services needed include substance abuse treatment readiness as well as outpatient and inpatient rehabilitation.

Incarcerated Individuals

This group may experience high risk behaviors associated with acquiring HIV, particularly drug and alcohol use. The continuation of HIV testing for incarcerated individuals and maintaining continuity of quality HIV and general medical treatment and care is essential. Services needed include awareness of the importance of HIV testing and treatment (if positive), substance abuse education and rehabilitation, mental health counseling, and awareness and access to PrEP.

People of Color

HIV and the associated risk factors disproportionately affect Black or African Americans (for both incidence and prevalence) and Hispanics/Latinos (for incidence). Services needed include health education and risk reduction provided in a culturally and linguistically sensitive manner.

Individuals with Mental Health Issues

People of all ages who experience mental health issues are particularly vulnerable to HIV, and individuals in this group generally lack access to adequate systems for basic HIV prevention education. Provision of health education/risk reduction by mental health counselors is essential to HIV prevention.

Individuals Traveling to Larger Cities (particularly New York City) for Socialization

In some cases, individuals who travel to larger cities, such as New York City, for socialization may not be aware of the risks associated with accessing social or sexual networks and may be at higher risk of infection than in the communities closer to home.

Immigrants

A high percentage of foreign-born individuals have immigrated to Long Island. Many immigrants escaped violence in their native countries, and there are high rates of illiteracy, even in the native languages of foreign-born individuals. For the N-S EMA immigrant population, health education/risk reduction must be delivered in a linguistically and culturally sensitive manner and would be best provided by someone with a mental health counseling background. Other jurisdictions have determined that peer counselors are a vital resource for this population.

Homeless/Transient Individuals

These hard-to-reach individuals often present with mental health needs, substance use, and other chronic diseases. Due to these factors, homeless and transient individuals are best served by peer counselors offering outreach with referral capability to both substance use and mental health treatment and counselors.

Nassau-Suffolk EMA, Nassau County. Participants noted opportunities for care improvement. For instance, they called for provider collaboration and noted the need for social supports to improve retention in care. They also advised adapting the integrated approach of health homes and FQHCs for HIV care. A call was also made for a system to coordinate referrals, including bi-directional data sharing for patients not linked to care.

In addition, participants outlined the care needs of special populations in the region. They expressed the importance of first meeting patients' fundamental survival needs, and suggested the use of a framework to address issues of socioeconomic status and HIV infection. They also expressed a need for expanded partner services. Similarly, participants raised the issue of retention among economically disenfranchised populations who must limit their phone use. They also noted high frequency of opiate addiction in Nassau County; given the relationship between addiction and HIV/HCV infections, they called for additional resources to be directed towards addressing substance abuse treatment. They also expressed concern regarding the limited availability of mental-health treatment for young MSM and called for additional medical providers capable of caring for transgender and gender non-conforming persons.

Finally, they requested the augmentation of prevention efforts. In particular, they advised providing incentives to encourage undocumented individuals to receive testing. They also cited the need to discuss sexual health and wellness, including PrEP.

Nassau-Suffolk EMA, Suffolk County. Participants called for additional social services to be offered to those not in care, and for better information dissemination regarding the Essential Health Plan and access to care. Participants noted that homophobia and transphobia have worsened the epidemic among MSM, LGBTQ, and transgender and gender non-conforming populations. There has also been a surge in syphilis rates among MSM. Research indicates a strong co-infection link between STIs and HIV infections. Participants emphasized the importance of providing care for MSM with STIs, as they are at high risk for acquiring HIV infection.

Participants also expressed concern about the relative lack of mental-health services, pointing out that these are unavailable at the FQHCs; they noted the lack of insurance acceptance by mental-health providers. There is also a waiting list at Article 31 mental-health facilities. Finally, participants called for additional behavioral health services on the east end of Suffolk County, in particular.

Northeast New York Region. Participants from this region emphasized that all communities should have equitable access to health care, and noted that additional resources must be directed towards communities in need. Beyond economic factors, participants also pointed out the impact of domestic violence on individuals at risk for or living with HIV/AIDS. They called for testing to be destigmatized by promoting routine testing for all. Participants also emphasized the importance of addressing factors that contribute to the significant impact of HIV on communities of color.

Participants pointed to the challenge of engaging individuals who are not virally suppressed. Noting the importance of intervention, participants pointed out that traditional outreach has not been met with great success and suggested the use of mobile-health units in communities at risk. They also called for posters, palm cards, and brochures in doctors' offices. Correctional facilities and jails were additionally noted as sites in need of prevention education, which would benefit inmates and releasees. Participants noted the need to discuss sexual health with youth.

Similarly, they urged medical providers to recognize that older adults may be engaging in high risk behaviors as well and should be offered HIV testing. They also called for increased participation from faith-based communities in prevention education activities. Finally, they pointed to the importance of coordinating service delivery so that individuals remain engaged in care.

Central New York Region. Participants noted that individuals needing access to substance use treatment services often cannot access care due to insurance issues. Participants also stated the need for increased funding for successful opioid overdose prevention services. Participants also urged providers to report cases in which insurance denies coverage to the State Department of Financial Services.

In addition, participants called for the State to further engage the Black heterosexual community in prevention and care services and address the stigma that discourages crucial engagement within this community. Participants expressed that the needs of heterosexual black women and men need to be identified, and engaging in further conversations with these communities needs to remain a priority.

Finger Lakes Region. Engagement and retention in care are paramount to achieving viral suppression and reducing transmission risk. Participants noted the need to monitor linkage and retention in the Rochester population. Participants noted an unfortunate lack of urgency which presents a challenge to achieving these goals. Participants shared that, since AIDS is no longer seen as a crisis, the response to it has become more moderate. In addition, major AIDS service centers need infusions of energy and resources. To promote better care in the region, participants encouraged new partnerships. In particular, they recommended engaging the faith community, which could serve as an agent of education and awareness. Participants similarly called for a patient-community collaboration with clinicians and non-clinicians.

Participants identified specific groups in need of services. They called for responsive interventions for heterosexual women of color, in addition to those for LGBTQ individuals of color. Participants also noted a gap in the availability of services for individuals in need of mental health programs.

Participants further called for enhanced prevention services, including additional marketing of PrEP to people of color. They called for peer and vocational opportunities for PWH. Participants also emphasized the importance of care retention, noting reasons people fall out of care, including internalized stigma, medication fatigue, and changes in services. On that last point, they called for better communication regarding service changes. They also advocated for changes in billing. For instance, they promoted expanding the number of providers who can bill for services. While they praised the ACA for making services billable, they also noted that billing is limited to clinicians. Noting that Centers for Medicare & Medicaid Services (CMS) changed its regulations regarding non-clinician billing (which is permitted with a doctor's order), they pointed out that each state must implement CMS rules on billable providers.

Western New York/Buffalo Region. Participants called for improvement to the testing culture in the region, specifically citing the need for more linkage to care in the field. They also noted the importance of physicians receiving training in having uncomfortable conversations (about sexual health, HIV status, etc.), and particularly in communicating a positive HIV diagnoses.

Given the health challenges presented by co-infection, participants expressed concern over rising syphilis rates, particularly among MSM, and the need for these individuals to be identified and given access to PrEP. Similarly, rates of hepatitis C have risen in recent years. While participants noted the efficacy of STI screening as an engagement strategy, they also pointed out the high expense. Noting that the onus of testing is placed on physicians, they called for data on success rates, and for funding interventions that are proven to be effective. Participants also noted that the time and effort devoted to reporting might be better spent in providing direct patient care.

Participants called for basic needs to be met—before and beyond other interventions. They also urged that greater emphasis be placed on behavioral interventions. Given the role that drugs play in transmission risk, participants expressed concern about the number of overdoses in the community, and about HIV-positive individuals also dealing with drug addiction.

Finally, participants noted the importance of prevention, and pointed out that some providers lack key information about PrEP. Similarly, they called for better marketing to a range of providers generally as a strategy for increasing referrals for care.

Hudson Valley Region. Focusing on engagement, participants in this region called for outreach strategies, advertising approaches, and testing messages that would be effective with specific populations, particularly the LGBTQ community. They also noted a gap in information regarding the needs of transgender and gender non-conforming persons, and they urged providers to solicit that information from the community. Participants emphasized the importance of instructing outreach workers in effectively approaching someone for testing. They also noted the importance of provider competency in discussing sex and LGBTQ issues, exhibiting cultural understanding, avoiding the use of stigmatizing language, and offering HIV tests (without disregarding the prospect that patients might have HIV). Participants suggested adding a course to the physician license renewal requirements to address these skills. In addition to urging open communication between pediatricians and their patients—and ensuring, whenever possible, that clinicians match the gender of their patients—participants called for transparent discussions between parents and preteens/teens and openness at schools, youth groups, and churches; they noted the efficacy of beginning such conversations before sexual activity begins, at age 11 or 12. Participants also expressed concern regarding insufficient housing, especially for undocumented individuals.

Turning to prevention, participants noted that many providers are not willing to prescribe PrEP for patients under 17 as well as youth fears about confidentiality and stigma should HIV status or PrEP use be discovered. They addressed the need to bring PrEP advertising to the online and

physical sites where youth gather (e.g., Adam4Adam, coffeehouses, etc.), and they urged primary-care providers to inform patients about the availability of PrEP.

Results of the Ending the Epidemic, From Blueprint to Action, Statewide Community Needs Assessment Input Conference Call, April 2016

Nearly 200 participants who joined this statewide community call opportunity identified the following needs:

- Housing: Access and stability of housing in the upstate, New York City, and Westchester, Rockland, and Putnam (Tri-County) regions
- Networking: Coordination and collaboration among regions and agencies for uniform data gathering and sharing across systems; inter- and intraregional planning and provision of services (including for mental health and substance use, medication adherence, and living with HIV)
- Training: Peer training and certification opportunities as well as payment for peer services; guidance on qualifications and non-discrimination in peer certification programs
- Mental health and substance abuse services: Specialty care providers in the upstate region; resources for response to the growing heroin and hepatitis C epidemic in the Nassau-Suffolk region
- PrEP: Accessibility for undocumented persons; information sharing from providers in the upstate (Rochester) region regarding PrEP best practices; PrEP best practices for engaging at-risk 18 to 26-year-olds, and for marketing geared toward women, men, and communities of color in rural areas
- Transportation: Funder limitations can present challenges.
- Adolescent prevention: Program outreach, services, and provider awareness in the upstate region; accessibility for youth; enhanced collaboration among regions; best practices for evidence-based school and college education and outreach
- Services for older adults: Prevention and testing programs, particularly those targeting older MSM
- Community involvement: Continued input and planning for regional group meetings (particularly in rural areas) regarding the implementation of *Blueprint* recommendations and the integrated plan
- Food insecurity and nutrition services: Funding and training for providers on responding to these needs and making appropriate referrals
- Support group and social services: Services specifically targeted to women to address barriers to care, including women in discordant relationships; the creation of local support groups (particularly for persons newly diagnosed with HIV) to alleviate pressure on local CBOs to provide services
- Reimbursement guidance: Information for providers regarding Medicaid redesign and new funding streams; assistance for clients regarding access to services and ADAP (for working PWH whose incomes are rising above income limits, and for those who are having difficulty accessing medical insurance coverage)
- Trauma counseling: Services and sensitivity for clients seeking or needing care and prevention and testing services (particularly for Native American community members)

- Legal services: Awareness about legal services, funded by the NYSDOH, for individuals and families affected by HIV/AIDS
- Epidemic demographics: Awareness of changing face of the epidemic and in- and out-migration of clients.
- Ending the Epidemic goals: Importance of ensuring that no communities or groups are marginalized or disproportionately affected; public messaging that ETE goals and efforts do not mean the end of prevention and care services.

Needs, Gaps, and Concerns Identified by HIV Planning Bodies Workgroup (HPBW)

HPBW members identified the following needs, broken down by planning body:

AAC Members

- Coordination of activities
- Increase number of people taking PrEP
- Linkage to care by non-clinical organizations
- Increase in programs that address the needs of women, especially women of color

HAB Engagement Committee

- Identification of service gaps
- Services in rural areas for individuals with hepatitis C, heroin addiction, and/or HIV; rapid testing for hepatitis C
- Housing for PWH
- PrEP for consumers at risk of HIV infection and their providers
- Trauma-informed care and prevention
- Nutrition services for food-insecure populations
- Better outreach with the communities at risk of HIV infection

HAB Best Practices Committee

- Health Homes and DSRIP information-sharing
- Sustainability of programs after the end of the ETE initiative in 2020
- PrEP options after the end of Gilead's PrEP Assistance Program
- Identification of transgender individuals in data systems
- Routinization of PrEP as a function of HIV testing, obstetric/gynecological care; inclusion of a system function in EMRs that requires a response in order to proceed forward
- More holistic care in Patient-Centered Medical Homes (PCMHs)
- Availability of all data in real-time
- Peer educator assessment process geared toward identifying personal biases and ability to work with specific populations

HAB Populations Committee

- Adequate funding to address health disparities and fully support effective implementation of ETE efforts
- Use of regional data to ensure strategies are appropriate for each region

- Culturally appropriate literature and other materials for each target audience
- Funding opportunities for CBOs and other non-medical providers to implement programs effectively; awareness of different perspectives on engaging clients (for instance, not excluding CBOs without medical staff from training doctors in PrEP, since those organizations have direct knowledge of prevention methods and clients)

NY EMA Planning Council Consumer Committee

- Access to treatment for those with hepatitis C/HIV co-infection
- Housing in the NY EMA, including the Tri-County Region
- Increased access and availability of PrEP and PEP
- Intensified efforts so PWH can achieve sustained viral load suppression
- Employment opportunities for PWH

NYC HIV Planning Group

- Targeted outreach and services for the transgender and gender non-conforming communities
- Access to health care services and supports for recently arrived immigrants
- Promotion of viral load suppression in PWH
- Increased accessibility of STI prevention and treatment services
- Availability of competent and relevant services and education for individuals during detention and after release
- Anti-poverty and anti-stigma interventions such as those addressing housing challenges
- Access to PEP and PrEP (including mechanisms to provide continuous coverage if patient is uninsured and/or underinsured) by increasing knowledge and awareness among providers and community members; developing effective methods for increasing the number of providers who offer PrEP and PEP in supportive environments with accurate information; and requiring emergency rooms to make PEP available, to train providers in PEP, and to provide PEP without discrimination or barrier

Nassau-Suffolk EMA Planning Council

- Services to address high levels of opioid use in both Nassau and Suffolk Counties; additional information on if and how opioids are linked to HIV/STI transmission
- Further information on drug interactions, given that the new CDC guidelines for pain management may prove challenging for those with HIV and substance issues
- Additional needle and syringe exchange programs; more promotion and resources for needle and syringe exchange programs.
- Linguistically competent providers and health care access for the many new immigrants on Long Island
- Universal health coverage, given that not all providers accept health insurance plans available through the ACA
- Available and affordable housing
- Greater availability of non-Ryan White funded mental health and substance use services (which currently have long waiting lists, with at least 200 individuals on a methadone

waiting list); coverage of intensive mental health and substance use services not currently available through Ryan White funded programs

- Local resources and culturally competent services for transgender men and women

d. Barriers

The most commonly identified barriers to prevention and care services in all regions involve social determinants of health that can affect access to needed services. Such factors include high and growing rates of poverty that put stress on service delivery; low literacy and lack of education; lack of adequate, affordable housing; domestic violence; and food insecurity. Key barriers related to housing were noted, including rising utility costs; long waits for Section 8 subsidies to free up long-term HOPWA assistance; reluctance of some landlords to rent to clients with criminal backgrounds; and the state of the economy, which has caused lost or reduced income.

Other commonly identified barriers include:

- It was noted that stigma can be a real barrier to seeking and remaining in care, pursuing testing, and securing housing.
- Mental health issues
- Substance use
- Limited accessibility of adequate transportation
- Shortage of dental, medical, substance abuse, and mental health providers and case managers available to address the specific issues faced by PWH
- Medicaid rules that restrict reimbursement and, therefore, limit access to transportation
- Issues of access, consent, payment, and confidentiality pose barriers to PrEP
- Co-morbidities
- Barriers to care for youth were noted; young persons cannot receive care without parental consent.

Participants in the Bronx cited numerous social determinants as barriers to health care. Among these were the need for housing for older adults who are HIV-positive; a lack of mental health services and education; a gap in the availability of nutrition services and affordable housing, and the trauma associated with placing families from one borough in single room occupancy (SRO)/housing elsewhere; the need for provider training regarding the impact of food security and nutrition on health outcomes, and referrals for patients for nutrition supportive services; ill-equipped shelters; the need for education about substance abuse and treatment options; need for transportation services; a lack of information regarding homelessness and poverty at care sites; a gap in the availability of directly observed therapy (DOT) for patients on ARVs; and institutional racism.

Participants in Upper Manhattan championed the removal of barriers to care. In particular, they recommended improving access to stable and affordable housing; requesting that pharmaceutical companies offer lower-cost treatments; and increasing medical and social services for historically underrepresented and marginalized populations.

Participants in the regional Spanish-speaking summit in NYC pointed to barriers affecting specific populations. An overall theme was the need for bilingual, bicultural providers who understand the needs of the community, as well as bilingual peer educators who are familiar with communities at risk.

Participants in the Central New York Region noted excessive travel distances and lack of adequate transportation as barriers to services. Participants in the Finger Lakes Region noted a lack of service providers who accept ADAP or Medicaid, particularly in the areas of mental health, dental services, and substance abuse treatment; and lack of effective outreach and education to deaf, Spanish-speaking, and immigrant communities due in part to lack of translation services. Participants in the Western region described significant illegal drug traffic, particularly in the Buffalo area, with drug use correlated with HIV vulnerability, as well as service inadequacies leading to extensive waiting periods for critical services.

Factors relating to transportation, hours of operation, and service site locations have been reported as barriers to accessing STD services, particularly in rural areas of NYS.

Barriers to access to hepatitis C services stem from inadequate reimbursement rates; lack of physician knowledge regarding HCV treatment and care; a need for increased provider awareness and understanding of protocols and guidelines; and a shortage of addiction specialists, psychiatrists, and support services.