

New York State Ending the Epidemic - Young Adult Advisory Group

Implementation Strategy Focus Area 1: Policy

The goal of this group is to develop implementation strategies for policy makers to implement appropriate, necessary, and effective policy and programming to end the HIV/AIDS epidemic in New York State (NYS) by the end of 2020.

Recommendation 1: Privacy & Consent

Recognizing that privacy and consent are key factors affecting an individual's decision to seek healthcare services, NYS should promote policies that grant youth and young adult's greater autonomy over their healthcare.

The NYS Department of Health (NYSDOH) must 1) repeal the law requiring parental consent for minors to begin treatment for HIV; and 2) provide alternatives to mailing Explanation of Benefits (EOB) forms (e.g. opt out, via email, in-person). Alternatively, if adult consent is required, NYS should provide minors the option to select an alternative to parental or legal guardian permission (e.g. counselor, aunt, social worker). To further protect confidentiality, the NYSDOH might also consider providing elective health insurance plans for young people.

Background: Currently, no other sexually transmitted infections (STIs) require that a minor must seek adult permission to receive treatment.

Recommendation 2: Comprehensive Sexual Education

The NYSDOH in joint efforts with the NYS Department of Education (NYSDOE), and other collaborative partners, should promote sexual and reproductive health education in grades 3-6 in order to better prepare today's youth to combat the epidemic. Questions related to sexual and reproductive health education should be incorporated into NYS Regents Examinations.

It is important to recognize that not all the responsibility falls on the content of education but those teaching it. We recommend that the departments continue to push and require health educators, to frequently be properly trained and tested on sexual health curriculum, especially HIV/STI prevention and treatment. It is also recommended that consistent training and education be required not only of health educators, but also of school health care providers. This will ensure that in the absence of proper sexual education in the curriculum, a well-trained source of information is still available to students. Lastly, we recommend that a coalition of school staff be created within each district of NYS to attend regional ETE-related meetings. This coalition would be tasked with pushing the implementation of these policy recommendations and promoting legislative reform related or similar to the Healthy Teens Act¹.

¹ The Healthy Teens Act amends the Public Health Law by requiring all local school districts develop age-appropriate and medically-accurate sex education curricula. The bill awards funding for school districts, boards of

Recommendation 3: Accommodations for People with Disabilities and Hard-to-Reach Populations

In accordance with the Americans with Disabilities Act (ADA), agencies should provide appropriate information and services to ensure all clients, *regardless of their age*, have agency over decisions regarding their health care. Just like their older counterparts, youth and young adults with disabilities – especially those living with and at risk of contracting HIV – require additional resources to ensure the highest quality of care. Resources offered on site should include interpreters, spoken language (i.e. Spanish, French, Arabic), nurse aides, request for service dogs, Video Relay Interpreting (VRI), and anything else necessary to accommodate clients' needs. Interpreters should be certified to convey care-specific language to those who are Deaf/Hard-of-hearing. Clients, no matter how many times they have accessed services at the institution in question, must be provided with the opportunity to give feedback regarding the adequacy of their services, in accordance with the ADA.

Additionally, NYS should consider a statewide system for mobile testing *and* treatment units, particularly to rural and otherwise hard to reach populations including incarcerated young people, those living in transitional housing (e.g. shelters, halfway homes, etc.), and undocumented immigrants.

Recommendation 4: Housing

We recommend that NYS ensures that new housing establishments (independent living) are allocated to transitional HIV negative and positive youth and young adults between the ages 16 and 29. Transitional and homeless agencies for youth and young adults should provide more resources than a 24-hour stay. NYS government-run supportive services should provide culturally competent and youth and young adult friendly services.

Recommendation 5: Provider Training

Cultural competency training must be provided to all hospital/clinic staff, including desk workers, nurses, and doctors, in order to provide comfortable and comprehensive services/healthcare to people who identify as Lesbian, Gay, Bisexual, Transgender or Queer (LGBTQ), deaf/hard-of-hearing, and youth with comorbidities. This requires continuous and regular training. Additionally, providing young people with culturally competent educational materials during their visits is necessary; this material should be in their preferred language. The cultural competency training should be updated as needed and approved by a community advisory board of LGBTQ youth.

cooperative education services and community-based organizations to provide comprehensive sex education programs for young people. Passage of the Healthy Teens Act is included as a Getting to Zero (GTZ) recommendation in the ETE Blueprint.

Implementation Strategy Focus Area 2: Housing

Youth and young adults who experience homelessness have a greater risk of contracting HIV, not being engaged in care, and not achieving viral suppression. Homelessness is traumatic and can put people at risk of violence and sexual assault. It can force them to engage in survival economies which increases the likelihood of further violence, sexual assault and encounters with law enforcement. These consequences can be even more severe for youth and young adults who age out of youth specific services at the age of 21. Ensuring housing for this key population is critical to ending the HIV/AIDS epidemic in NYS. To address the immediate housing needs of New York's youth and young adults, we recommend the following:

Recommendation 1: Amend the Runaway and Homeless Youth Act

Amend the Runaway and Homelessness Youth Act² to serve youth and young adults until their 25th birthday; the current age limit is 21 years old. The current age limit does not allow young adults, particularly those coming out of foster care, enough time to complete vocational training or college. For many young adults, the current age limit has served as a pathway into the shelter system. The extension to 25 would allow for young adults to obtain gainful employment, which will make it easier to acquire stable housing.

Recommendation 2: Increase Access to Stable and Permanent Housing

The AIDS Institute should work with collaborative partners, such as the NYS Attorney General's Office and Division of Human Rights, to develop a plan to ensure the promotion of equal justice and enforcement of the law protecting vulnerable New Yorkers from source of income discrimination and other forms of housing discrimination based on identity (i.e. race and gender). We recommend regular and consistent testing to identify homeless youth and young adults living with HIV. We support "Ban the Box/Fair Chance Act"³ legislation to increase gainful employment, ensure steady income, and expand access to stable and permanent housing among youth and young adults. We encourage expanding "Ban the Box" legislation to the housing application process where landlords would be barred from asking applicants about prior convictions before determining if the applicant qualifies as a suitable tenant.

Recommendation 3: Create Oversight Committee to Address Issues Related to Homelessness Among Youth and Young Adults

² The Runaway and Homeless Youth Act authorizes community-based runaway and homeless youth projects to provide temporary shelter and care to runaway or otherwise homeless youth who are in need of temporary shelter, counseling, and aftercare services. For more information please see Vol. 81, No. 244 of the U.S. Department of Health and Human Services' Federal Register.

³ In June 2015, the Fair Chance Act (FCA) – otherwise known as the "Ban the Box" Act – was signed into law in NYC. The FCA helps ensure that job applicants are not barred from employment due to their conviction history. It requires all employers to wait until they offer an applicant a job before asking about their conviction history or doing a background check. This means ads, applications, and interview questions cannot include inquiries into an applicant's criminal record. For more information please see the NYC Human Rights website's FCA Campaign page.

The AIDS Institute should collaborate with partners such as the Office of Temporary and Disability Assistance (OTDA) to create an Oversight Committee to address issues related to homelessness among adolescent and young adult populations in NYS. The Oversight Committee should have diverse membership including directly affected youth and young adults (i.e. homeless, runaway, throwaway), staff who directly interact or work with youth and young adults, an AIDS Institute representative and an OTDA representative. The Oversight Committee would be tasked with finding tenant rights statements that may already have been developed by social service organizations and advocacy groups focused on homelessness. In the case that a tenant rights statement exists, the goal of the Oversight Committee would be to ensure youth representation in this document. If it does not exist, the Committee would be tasked with creating a “Bill of Rights” and with taking action on grievances, concerns, and complaints from tenants about housing issues.

The Bill of Rights would be composed of concise statements of the rights of youth and young adult tenants and the items and services they are entitled to receive. The Bill of Rights would outline the rights of tenants and requirements of staff members and the agency. It would list the contact information for tenants to provide grievances, concerns, and complaints to the Oversight Committee and other agencies. Example statements may include, but are not limited to: tenants have the right to receive free HIV testing, consulting, and access or referral to treatment; tenants have the right to provide grievances, concerns, and complaints with no repercussions. The final document should be prominently displayed.

The primary task of the Oversight Committee would be to receive, review, and take action on grievances, concerns, and complaints regarding youth and young adult-related housing and shelter issues in a timely manner. The Oversight Committee would provide recommendations to ensure the continued enforcement of youth and young adult tenant rights statements. The Oversight Committee should meet at least every six months to review grievances.

Recommendation 4: Establish a New York State Community Action Board

Create a NYS Community Action Board (CAB) composed of youth and young adults who are or have been homeless or used housing services. The purpose of the CAB is to: discuss issues and problems surrounding adolescent and young adult homelessness, housing access, and housing conditions; create and draft recommendations and strategies to eliminate housing issues; and advise NYS government, housing organizations, and other related groups and individuals on laws and regulations regarding housing issues. The CAB would work closely with the Oversight Committee to discuss, recommend, and advise on topics.

The CAB would be made of members representing different regions of NYS, the regions could be similar to RHIOs, with at least two (2) members from each region. The members can nominate themselves or be nominated by others to service on the CAB. AIDS Institute would determine representatives, coordinate and moderate meetings, and provide any additional support. The CAB would meet in person at least once a year and conduct a minimum of three

(3) additional meetings via conference call or video for a total of four (4) meetings a year. Subcommittees could be formed to work on specific issues and should meet as frequently as needed.

Recommendation 5: Comprehensive Outreach Team

The AIDS Institute, in conjunction with the Division of Human Rights and other state agencies, as appropriate, should put together a Comprehensive Outreach Team (COT) which should include a lawyer, a NYSDOH representative, a pharmacy representative, and a representative from the AIDS Institute. This team should be flexible, have experience or indicate willingness to work with youth and young adults who experience homelessness, are HIV positive or have a greater risk of contracting HIV. The COT's main purpose would be to do outreach to housing programs in order to update staff and clients on new initiatives, new laws relevant to at-risk youth, job opportunities or any updated information that could benefit clients. The COT should also make time to answer any questions and/or concerns clients may have. Additionally, it is our recommendation that this team be available to answer any questions via email and video chat (e.g. Skype, Oovoo, FaceTime).

Implementation Strategy Focus Area 3: Treatment and Prevention

The goal of this group is to provide recommendations about treatment and prevention initiatives pertaining to HIV/AIDS for young adults and youth across NYS. To address these pressing needs by the end of 2020, we recommend the following:

Recommendation 1: Comprehensive Sexual Education focused on Case Management, Counseling and Pre-Exposure Prophylaxis and Post-Exposure Prophylaxis (PrEP/PEP) Access

There is a continued need for comprehensive sexual health education for youth and young adults. However, many NYS public schools lack the capacity to provide sexual health education. We therefore recommend that schools establish partnerships with local health care centers, hospitals, adolescent specialized care centers and/or nonprofits to have health educators provide sexual health education for students and competency trainings for school staff, routinely. These trainings are in effort to not only educate but to sensitize students and staff about sexual health and available services in local areas. We also recommend that local schools, in collaboration with health educators and other community centers, host information seminars for parents, guardians, and other community leaders. “Sexual Health Toolkits” should also be disseminated at these seminars.

“Sexual Health Toolkits” should indicate a range of services that each service provider provides, namely Case Management, PrEP and PEP Access, Counseling, Housing, Medical Site, etc. It should provide further insight into the operational hours and days, age range access and intended target communities of these services. This would help direct individuals in need to services specifically tailored to the needs of youth at risk of contracting HIV/AIDS and youth living with HIV/AIDS. The toolkit would educate teachers about the scope of services and their demographics, paving a navigation system of available options and alternatives. Including a brief history and a client profile from each service provider would link the experience and background with the foreseeable development of youth within their programs. Another feature that should be included in the toolkit is a map displaying the geographic location of each service provider to clearly illustrate the proximity of each program.

The sexual health curricula for students play a significant role in exposing them to basic information regarding HIV/AIDS and STDs. However, evidence-based curricula may often utilize outdated epidemiologic data. We therefore recommend that NYS funded initiatives like the Comprehensive Adolescent Pregnancy Prevention and Personal Responsibility Education Program (CAPP & PREP)⁴ provide updated supplemental information that can be added to the curricula. This curriculum should be accessible and peer-led to include robust information

⁴ Comprehensive Adolescent Pregnancy Prevention (CAPP) is an initiative funded by the NYSDOH to support community-based efforts to reduce the risk of pregnancies, STDs, and HIV among NYS adolescents. The CAPP initiative began January 1, 2011 with funding for 50 CAPP projects awarded to local community-based organizations throughout the state. In July, eight additional projects were funded through the CAPP initiative with federal Personal Responsibility Education Program (PREP) funding.

supporting risk reduction that outlines signs and symptoms of acute HIV infection, PrEP & PEP and education around HIV stigma.

Recommendation 2: PrEP/PEP

Utilize already existing mobile apps or create new apps specific to PrEP and PEP to help monitor individuals who utilize PrEP or PEP, or create new mobile apps that are specific to the utilization of PrEP and PEP. These apps would be link individuals who use PrEP or PEP to a peer navigator, primary care physician, and/ or pharmacist. These apps would help the person who is working with the individual to monitor adherence to the medication they are on. If an individual missed their dose within the two hour time frame they set to take their medication, the person monitoring could send them a reminder via the mobile app, using discretion to protect confidentiality. These reminders would only be available through the mobile app. No text messages, reminders or push notifications would be available with these apps for confidentiality purposes. Under appropriate circumstances, age restrictions for youth under the age of 18 **should not** require parental consent to access PrEP or PEP. These medications should be made accessible to youth under the age of 18 without parental consent because it goes against the protection and rights of confidentiality for the youth receiving such services. Youth accessing PrEP or PEP as a preventative measure against contacting HIV should be treated as those who are 18 and older. They should be subjected to the same consent process and given the same confidentiality rights as those treated as adults.

Recommendation 3: Increase General STI Testing

As the prevalence of co-infectious diseases, Hepatitis C (HCV) and HIV, increases, it is imperative to increase both HIV and HCV testing; specialized supportive services need to be made available to co-infected individuals, as well as care coordination. The AIDS Institute, along with other partners, such as the New York City Department of Health and Mental Hygiene (NYCDOHMH), The NYS Office of Alcoholism and Substance Abuse Services (OASAS) and local health departments, need to collaborate to ensure the increase and improvement of treatment and prevention services. It is our recommendation that HCV testing become routinely offered and completed, readily available and offered alongside HIV testing.

In addition to testing, it is imperative to raise awareness among care providers, school faculty and staff. This can be implemented through workshops and trainings at yearly retreats. It is also our recommendation to strategically place care coordination and supportive services for those co-infected with HCV and HIV in the areas around schools, local community centers medical facilities, and adolescent substance use treatment centers.

Implementation Strategy Focus Area 4: Marketing

The Young Adult Advisory Marketing group is charged with developing strategies for implementation across NY State to promote and market healthier practices and preventative strategies to end the HIV epidemic in youth by the end of 2020.

Sub-Focus Area 1: ETE and Prevention Education

Recommendation 1: Promote the existing Clinical Education Initiative CE courses to primary care providers.

Most youth, especially those in rural areas, rely on their primary care physician (PCP) as the gatekeeper to PrEP. We recognize that comfort with managing PrEP is not yet ubiquitous among PCPs in NYS. Regular promotion of online PrEP Continuing Education courses(s) would encourage more providers to prescribe, manage, and advocate for PrEP with their patients. Tactics for promotion could include supporting existing channels that have newsletters/email lists - the CEI and MSSNY - and possibly public charges by the Governor. Additionally, promoters may want to use ETE to help sell the importance/urgency of PrEP education.

Recommendation 2: Develop user-friendly website/webpage for health and peer educators to disseminate new educational tools.

High school health programs would benefit from expanded curriculum on PrEP and ETE. The AIDS Institute should explore allocating resources to develop PowerPoints, interactive activities, and lesson plans for use in classroom and community settings. Also, research shows the effectiveness of peer education in sex education, so we recommend developing a (or repurposing an existing) peer advocate's tool for sharing PrEP and ETE information. Notably, a peer advocate's tool should include strategies for using social media to reach out to personal peer groups and include graphical elements, including infographics, profiles pictures, cover pictures, etc.

Recommendation 3: Integrate tools (app) for mail order PrEP and telemedicine into educational courses and tools for both providers and educators.

One of the barriers to regular PrEP use is travel to the doctor's office, lab, and pharmacy. There are some apps, like Nurx, that are exploring the concept of home delivery of PrEP. An app like this, perhaps integrated with novel telemedicine/at-home testing, could help eliminate these burdensome trips. We suggest integrating discussions of such apps and telemedicine into educational courses for providers as well as tools for health educators. As such apps/telemedicine become more advanced, we recommend establishing specific promotional campaigns to advertise these services to the diverse communities that would benefit from this convenience.

Sub-Focus Area 2: Social Media

Recommendation 1:

The AIDS Institute, NYSDOE, and other collaborative partners should develop an effective method to disseminate information about ETE and PrEP to youth through social media. First, we suggest identifying any images that are currently associated with the ETE campaign and PrEP. Youth should be involved in this process to evaluate the success of these images and or previous strategies. From this, we recommend establishing a logo for both the ETE campaign and PrEP, as logos are an effective recognition method for all age groups. In addition to a logo, we suggest creating a short slogan to accompany each logo. Youth will not respond to long slogans, rather, the instant gratification of a short slogan and the ability to memorize said slogan will appeal to young adults through “brand recognition”. We suggest that the slogans be no more than 150 characters, similar to a tweet. Utilizing humor when creating slogans will be beneficial (e.g., “PrEP: the *other* blue pill. It’ll keep you going for longer than Viagra”). After a logo and slogan have been tested via feedback from various youth from all communities, we recommend developing strategies to disseminate each logo and accompanying slogan on popular, high-traffic social media websites such as Snapchat, Instagram, and Facebook. Branding with images and slogans can create synergy between various social platforms. Further, we suggest taking advantage of platform-specific tools like Snapchat filters and “discover” stories/content to become more integrated in the platform’s community. One of the potential advantages of social media is the anonymous or semi-anonymous nature of posting and sharing. With the aforementioned platforms, and exploring newer up-and-coming platforms, we recommend establishing an anonymous Q&A structure for youth to ask questions about ETE and PrEP. Managing social media can be a time-consuming activity, but considering that youth spend an increasing amount of time on such platforms, we suggest directing resources toward providing consistent social media management and communication to ensure a robust and well-executed social presence for ETE.

Sub-Focus Area 3: Marketing Placement

Recommendation 1:

We are aware of the current ETE strategies to market HIV Prevention and PrEP. In future marketing strategies, we recommend identifying key locations where youth congregate, as these are the areas where marketing materials will reach this population. We also recommend strategic placement at these locations to prevent youth from feeling specifically targeted and overwhelmed by advertisements. Further, we suggest speaking to various youth from different communities regarding what type of marketing materials appeal to current young adults. Finally, we recommend supporting existing groups charged with engaging all communities in the development of these marketing tools. These marketing tools must appeal to all communities and be diverse in nature to express to youth that *all* voices must be heard and represented. For example, creating a cyclic group of youth to review any/all materials that

will be circulated to the community prior to implementation. Youth should be constantly replaced by other new and diverse youth to avoid redundant feedback. Incentives could be given to maintain encourage attendance during each cycle and ensure completion. These youth should be high risk, making sure to be inclusive of IV drug using youth. These youth should then also be connected to other resources, e.g., peer education.