

Government/Community Partnerships to Shape Public Health Policy to End the HIV Epidemic in New York

2021 Public Health Law Conference
Thursday, September 23, 2021, 2:30-3:45pm

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Kimberleigh Smith, MPA
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Callen-Lorde Community Health Center

Presenters



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Agenda

- Early Days of the HIV Epidemic in New York City and the U.S.
- Ending the HIV Epidemic in New York State: Birth of a Movement
- Government/Community Partnership Case Study 1: Sexual Health Clinics
- Government/Community Partnership Case Study 2: Securing Minors' Right to Consent to HIV Services
- Ending the HIV Epidemic in New York State: Policy Successes
- The Denver Principles
- Discussion

An aerial photograph of New York City, showing the dense urban landscape and the Manhattan skyline. The image is overlaid with a semi-transparent blue and purple gradient. The text is centered in a white, bold, sans-serif font.

Early Days of the HIV Epidemic in New York City and the U.S.

Early Days of the HIV Epidemic, U.S.

CENTERS FOR DISEASE CONTROL
MORBIDITY AND MORTALITY WEEKLY REPORT
July 3, 1981 / Vol. 30 / No. 25

Epidemiologic Notes and Reports

Kaposi's Sarcoma and *Pneumocystis* Pneumonia Among Homosexual Men – New York City and California

During the past 30 months, Kaposi's sarcoma (KS), an uncommonly reported malignancy in the United States, has been diagnosed in 26 homosexual men (20 in New York City [NYC], 6 in California). The 26 patients range in age from 26-51 years (mean 38 years). Eight of these patients died (7 in NYC, 1 in California) and 8 within 24 months after KS was diagnosed. The diagnoses in all 26 cases were based on histopathological examination of skin lesions, lymph nodes, or tumor in other organs. Twenty-five of all the 26 patients were white, 1 was black. Presenting complaints from 20 of these patients are shown in Table 1.

Skin or mucous membrane lesions, often dark blue to violaceous plaques or nodules, were present in most of the patients on their initial physician visit. However, these lesions were not always present and often were considered benign by the patient and his physician.

A review of the New York University Coordinated Cancer Registry for KS in this age group at the New York University Hospital from 1961-1979.

Seven KS patients had serious infections diagnosed after their initial physician visit. Six patients had pneumonia (4 biopsy confirmed as due to *Pneumocystis carinii* [PC], and one had necrotizing otitis media of the central nervous system). One of the patients with *Pneumocystis* pneumonia also experienced severe, recurrent, herpes simplex infection, extensive candidiasis, and cryptococcal meningitis. The results of tests for cytomegalovirus (CMV) infection were available for 12 patients. All 12 had serological evidence of past or present CMV infection. In 2 patients for whom culture results were available, CMV was isolated from biopsy, urine and/or lung of all 2. Past infections with amebiasis and hepatitis were commonly reported.

TABLE 1. Presenting complaints in 20 patients with Kaposi's sarcoma

Presenting complaint	Number (percentages) of patients
Blue-red-purple skin	12 (60%)
Blue-red-purple lymphadenopathy	4 (20%)
Uterine mass lesion only	1 (5%)
Regional adenopathy plus genital ulcers	1 (5%)
Weight loss and fever	2 (10%)
Weight loss, fever, and pneumonia	2 (10%)
Fever due to <i>Pneumocystis carinii</i>	7 (35%)

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES / PUBLIC HEALTH SERVICE

**THE NEW YORK TIMES,
FRIDAY, JULY 3, 1981**

A20 L

RARE CANCER SEEN IN 41 HOMOSEXUALS

Outbreak Occurs Among Men in New York and California — 8 Died Inside 2 Years

By LAWRENCE K. ALTMAN
Doctors in New York and California have diagnosed among homosexual men 41 cases of a rare and often rapidly fatal form of cancer. Eight of the victims died less than 24 months after the diagnosis was made.

- In June and July 1981, the Centers for Disease Control and Prevention (CDC) publishes “Pneumocystis Carinii Pneumonia” and “Karposi’s Sarcoma and Pneumocystis Among Homosexual Men – New York City and California” Morbidity and Mortality Weekly Reports.
- One month later, the New York Times publishes “Rare Cancer Seen in 41 Homosexuals.”

Sources: Michael S. Gottlieb *et al.*, *Pneumocystis Pneumonia – Los Angeles*, 30 (21) MORBIDITY & MORTALITY WEEKLY REPORT 1-3 (Jun. 5, 1981); Alvin Friedman-Kien *et al.*, *Karposi’s Sarcoma and Pneumocystis Among Homosexual Men – New York City and California*, 30 (25) MORBIDITY & MORTALITY WEEKLY REPORT 305-308 (Jul. 3, 1981); Lawrence K. Altman, *Rare Cancer Seen in 41 Homosexuals*, N.Y. TIMES (Jul. 3, 1981), available at <https://www.nytimes.com/1981/07/03/us/rare-cancer-seen-in-41-homosexuals.html>.

Early Days of the HIV Epidemic, New York City and U.S.

- In January 1982, 80 activists gather in writer Larry Kramer's apartment in New York City (NYC) to discuss "gay cancer" and raise funds for research, founding Gay Men's Health Crisis.
- In September 1982, CDC uses "AIDS" for the first time and releases its first case definition.
- In 1983, New York State (NYS) mandates AIDS case reporting by doctors and laboratories.



Early Days of the HIV Epidemic, New York City and U.S.



- In June 1983, activists take over the National AIDS Forum stage in Denver and issue a statement on the right of people with AIDS to be involved in AIDS policy decisions (“The Denver Principles”).
- Demonstrations and rallies continue to take place in NYC and across the U.S.

Sources: HIV.gov, A Timeline of HIV and AIDS (last accessed Sept. 19, 2021), available at <https://www.hiv.gov/hiv-basics/overview/history/hiv-and-aids-timeline>; UNAIDS, The Denver Principles (1983) (last accessed Sept. 19, 2021), available at https://data.unaids.org/pub/externaldocument/2007/gipa1983denverprinciples_en.pdf; Nurith Aizenman, *How to Demand a Medical Breakthrough: Lessons from the AIDS Fight*, NPR (Feb. 9, 2019), available at <https://www.npr.org/sections/health-shots/2019/02/09/689924838/how-to-demand-a-medical-breakthrough-lessons-from-the-aids-fight>.

Early Days of the HIV Epidemic, U.S.

- In January 1985, CDC revises the AIDS case definition, noting AIDS is caused by a newly identified virus. CDC issues provisional guidelines for blood screening.
- In September 1985, over four years since the first cases were reported, President Ronald Reagan publicly mentions AIDS for the first time. Two years later, he makes his first public speech about AIDS.



Sources: HIV.gov, A Timeline of HIV and AIDS (last accessed Sept. 19, 2021), available at <https://www.hiv.gov/hiv-basics/overview/history/hiv-and-aids-timeline>; Tim Fitzsimons, *LGBTQ History Month: The Early Days of America's AIDS Crisis*, NBC News (Oct. 15, 2018), available at <https://www.nbcnews.com/feature/nbc-out/lgbtq-history-month-early-days-america-s-aids-crisis-n919701>; ACT UP, Capsule History (last accessed Sept. 19, 2021), available at <https://actupny.org/documents/capsule-home.html>.

Early Days of the HIV Epidemic, New York City



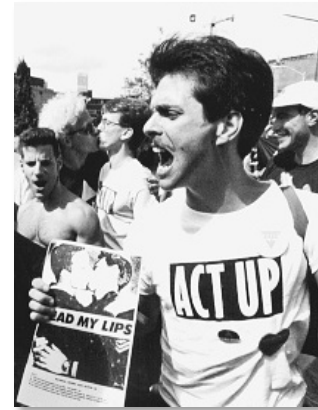
- In October 1985, following a years-long battle between government and public health officials and community members, NYS authorizes local health departments to close – as the New York Times put it – “homosexual bathhouses and other places where ‘high-risk sexual activities’ occur.” The state health council issuing the regulatory amendment includes “anal intercourse and fellatio” in its definition of high-risk sexual activities.

Source: Maurice Carroll, *State Permits Closing of Bathhouses to Cut AIDS*, N.Y. TIMES (Oct. 26, 1985), available at <https://www.nytimes.com/1985/10/26/nyregion/state-permits-closing-of-bathhouses-to-cut-aids.html>.

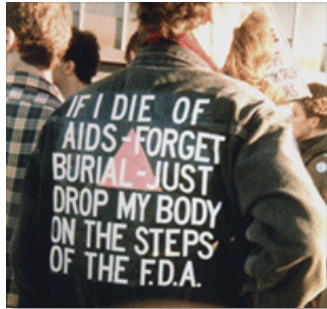
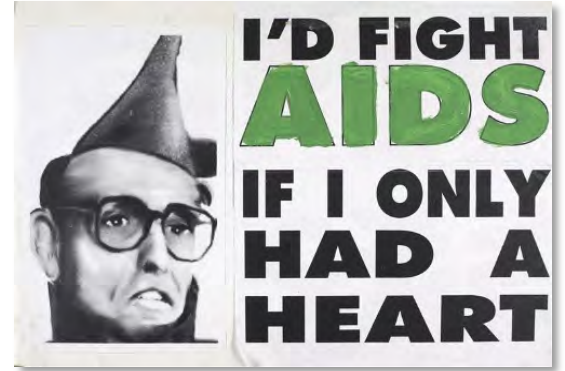
Early Days of the HIV Epidemic, New York City and U.S.



- In March 1987, advocates form AIDS Coalition to Unleash Power (ACT UP) in NYC and begin holding protests at City Hall and City agencies, elected officials' offices, Wall St., hospitals, churches, public parks, and other venues.

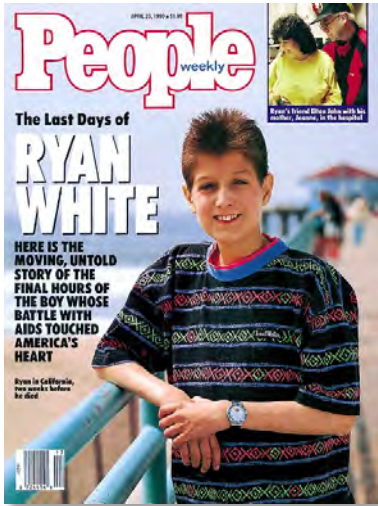


Early Days of the HIV Epidemic, New York City and U.S.



Sources: ACT UP, Act Up Accomplishments – 1987-2012 (last accessed Sept. 19, 2021), available at <https://actupny.com/actions/>; ACT UP, Capsule History (last accessed Sept. 19, 2021), available at <https://actupny.org/documents/capsule-home.html>.

Early Days of the HIV Epidemic, U.S.



- In 1984, 13-year-old Ryan White is diagnosed with AIDS following a blood transfusion. Over 160 parents and teachers sign a petition demanding his expulsion from school. Despite statements from his doctors confirming he poses no risk to others, White is expelled. After a lengthy legal battle, the Indiana Department of Education rules in favor of White's readmittance.
- White dies in April 1990, a few months before Congress passes the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, which funds cities, states, and community-based organizations to provide primary medical care and support services to people with HIV. The program provides over \$220 million in funding in its first year, and today, reaches more than half of all people diagnosed with HIV in the U.S.

Sources: Health Resources & Services Admin., Ryan White HIV/AIDS Program, Who Was Ryan White? (last accessed Sept. 19, 2021), available at <https://hab.hrsa.gov/about-ryan-white-hivaids-program/who-was-ryan-white>; Bill Shaw, *Candle in the Wind*, PEOPLE (Apr. 23, 1990), available at <https://people.com/archive/cover-story-candle-in-the-wind-vol-33-no-16/>.

Early Days of the HIV Epidemic, New York City



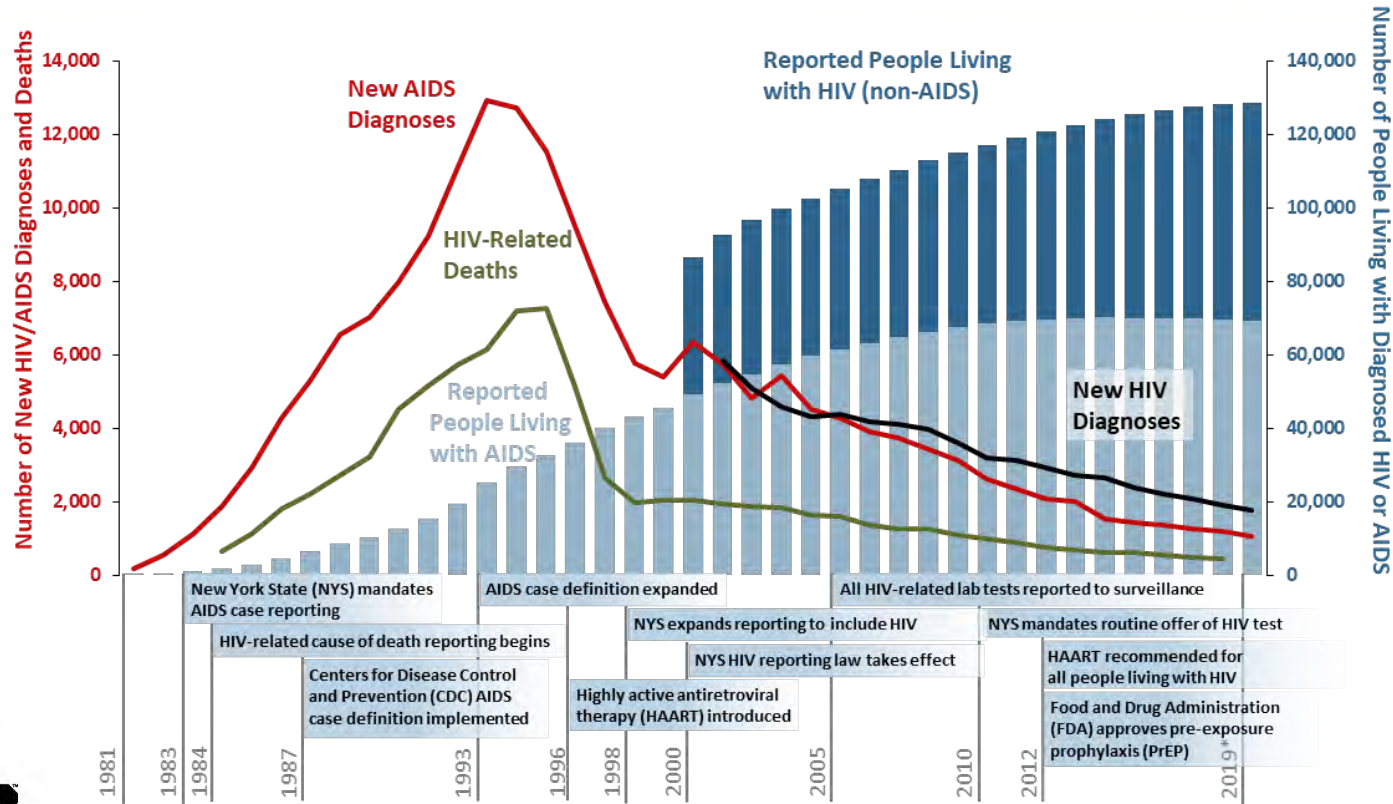
- In January 1988, NYC Health Commissioner Dr. Stephen Joseph secures approval from the state health administration to launch a needle exchange pilot in NYC, framing it as a clinical trial to combat strong opposition by the NYPD, local and state government officials, and community members. In November 1988, the first clients make their way through police barricades and demonstrators to enter the pilot's single site at the NYC Department of Health and Mental Hygiene (NYC DOHMH) in Lower Manhattan.

Source: Warwick Anderson, *The New York Needle Trial: The Politics of Public Health in the Age of AIDS*, 81 (11) *AM. J. PUBLIC HEALTH* 1506-1517 (Nov. 1991).

Early Days of the HIV Epidemic, New York City and U.S.

- In 1992, AIDS becomes the number one cause of death for men ages 25 to 44 in the U.S.
- In June 1995, the FDA approves the first protease inhibitor, leading the way for highly active antiretroviral therapy (HAART).
- By October 1995, over 500,000 AIDS cases have been reported in the U.S.
- In 1996, for the first time since the beginning of the epidemic, the annual number of new AIDS cases in the U.S. declines.

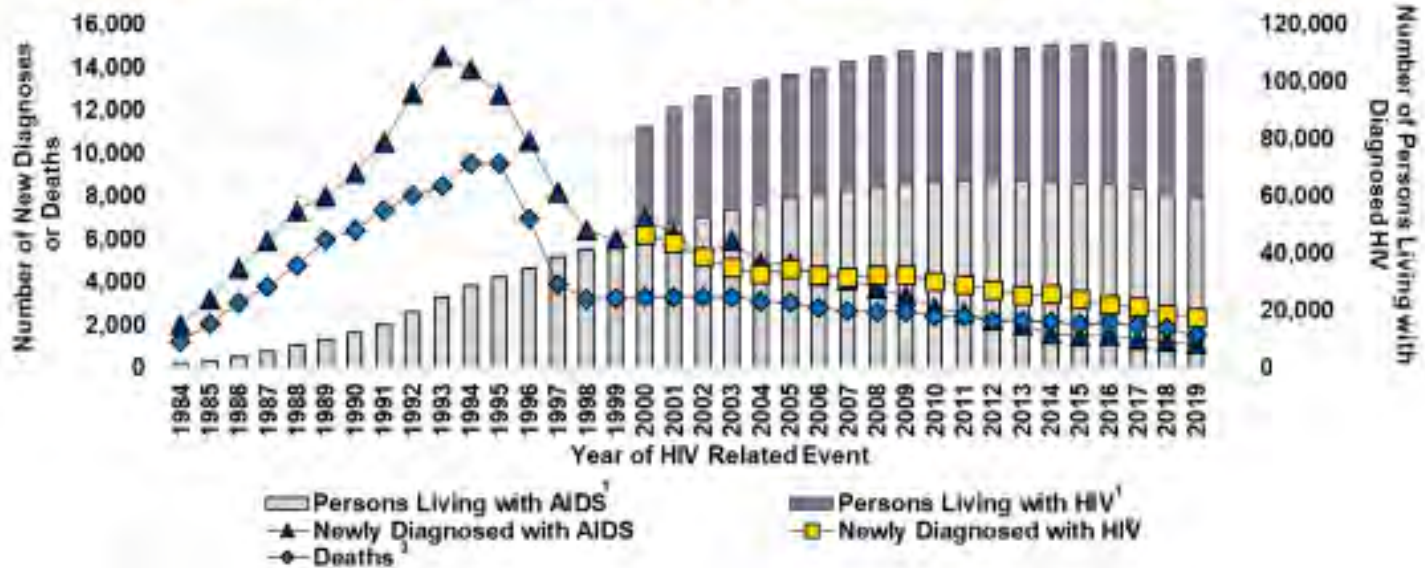
HIV and AIDS in New York City, 1981-2019



Source: N.Y.C. DEP'T OF HEALTH & MENTAL HYGIENE, HIV SURVEILLANCE ANNUAL REPORT, 2019 (Dec. 1, 2020), available at <https://www1.nyc.gov/assets/doh/downloads/pdf/dires/hiv-surveillance-annualreport-2019.pdf>. As reported to N.Y.C. Dep't of Health & Mental Hygiene by Mar. 31, 2020.

HIV and AIDS in New York State, 1984-2019

Trends in HIV Related Outcomes, NYS, 1984-2019*

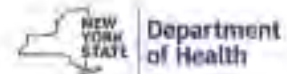


¹Excludes persons with AIDS with no evidence of care for 5 years and persons with diagnosed HIV (non-AIDS) with no evidence of care for 8 years.

²HIV named reporting began in June 2000

³Includes deaths from all causes (death data from 2019 is incomplete)

*Data as of June 2020



An aerial photograph of New York City, showing a dense urban landscape with numerous skyscrapers and buildings. The image is overlaid with a semi-transparent blue and purple gradient. The text is centered in a white, bold, sans-serif font.

Ending the HIV Epidemic in New York State: Birth of a Movement

Ending the HIV Epidemic in NYS: Birth of a Movement



- In March 2012, following the We Can End AIDS March timed to coincide with the International AIDS Conference, 13 activists are arrested outside the White House while protesting the federal government's inadequate response to the HIV epidemic.
- The following month, 10 activists are arrested outside City Hall in NYC while protesting Mayor Bloomberg's housing and supportive services policies for people with HIV. The demonstration is part of ACT UP's 25th anniversary march and rally.

Sources: Michael K. Lavers, *AIDS 2012: 13 HIV/AIDS Protestors Arrested in Front of White House*, WASHINGTON BLADE (Jul. 24, 2012), available at <https://www.washingtonblade.com/2012/07/24/aids2012-13-hivaids-protesters-arrested-in-front-of-white-house/>; ACT UP, ACT UP Protests Wall Street Over 1,000 Take to the Streets Demanding a Wall Street Tax for Health Care (Apr. 25, 2012), available at <https://actupny.com/act-up-protests-wall-street/>.

Ending the HIV Epidemic in NYS: Birth of a Movement



- In 2013, community stakeholders come together to review the statewide response to the HIV epidemic and demand action by Governor Cuomo.
- In October 2014, Governor Cuomo appoints a task force of over 60 community leaders, providers, public health professionals, government officials, and people with HIV to develop a plan to end the HIV epidemic in NYS.

NYS Blueprint for Ending the HIV Epidemic

- In March 2015, Governor Cuomo releases the task force's **NYS Blueprint for Ending the HIV Epidemic**, a set of recommendations organized around three strategies:



1. Identify people with HIV who remain undiagnosed and link them to care;
2. Link and retain people diagnosed with HIV in care to maximize virus suppression so they remain healthy and prevent further transmission; and
3. Provide access to HIV pre-exposure prophylaxis (PrEP) for people at high risk for HIV infection

End AIDS NY 2020 Coalition



- Following the release of the NYS Blueprint for Ending the HIV Epidemic, community stakeholders launch the **End AIDS NY 2020 Coalition**, a coalition of over 60 organizations committed to holding local and state government officials accountable for implementing the blueprint recommendations.



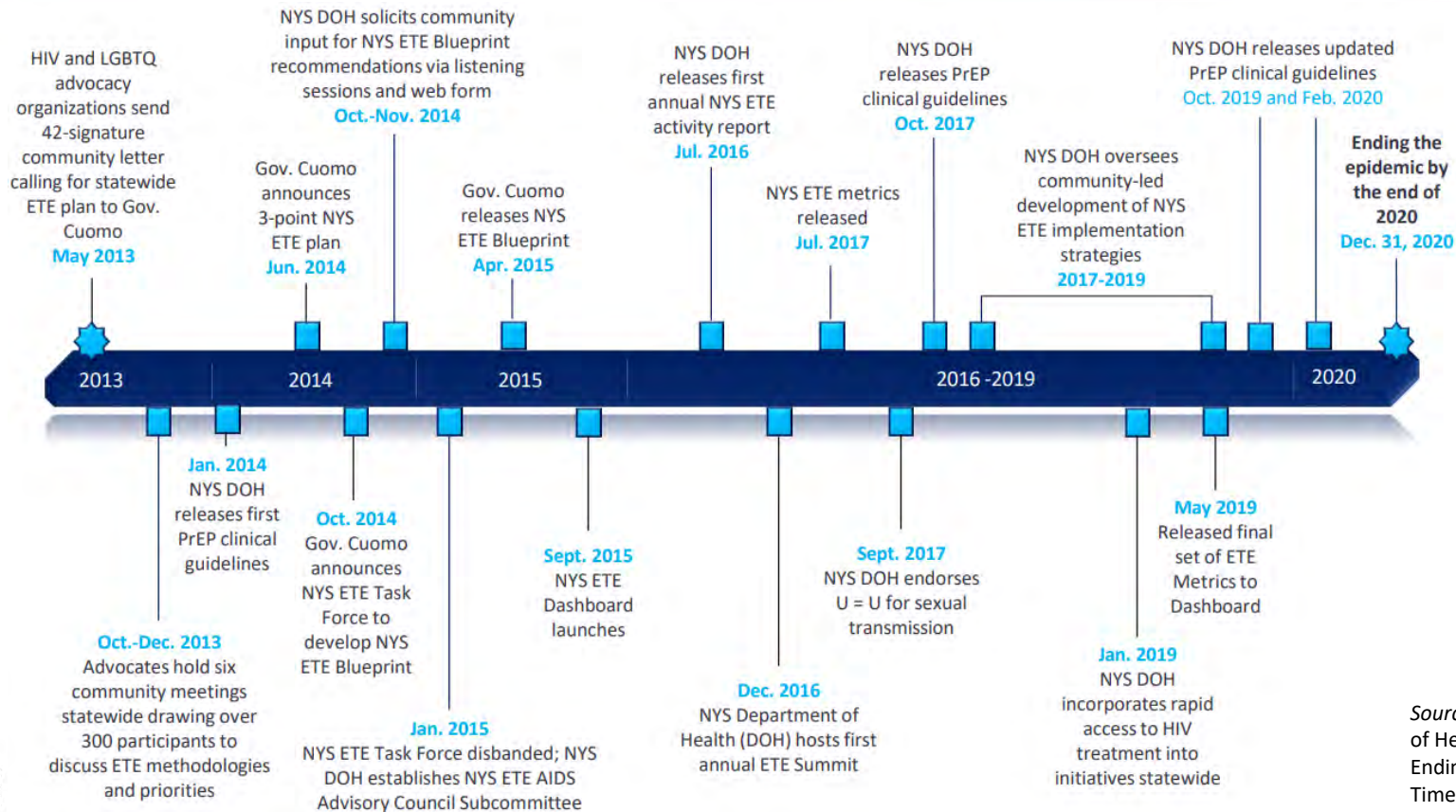
NYS and NYC Community Planning Bodies and Advisory Groups

- The End AIDS NY 2020 Coalition works closely with the **NYS AIDS Advisory Council** and NYC DOHMH-affiliated planning bodies and advisory groups, including the **HIV Health and Human Services Planning Council of New York**, **New York City HIV Planning Group**, and **Women's Advisory Board**.



Sources: N.Y.S. Dep't of Health, N.Y.S. AIDS Advisory Council (last accessed Sept. 19, 2021), available at <https://www.health.ny.gov/diseases/aids/providers/workgroups/aac/index.htm>; HIV Health & Human Services Planning Council of New York (last accessed Sept. 19, 2021), available at <https://nyhiv.org/>; N.Y.C. HIV Planning Group (last accessed Sept. 19, 2021), available at <http://nychpg.org/>.

NYS Ending the HIV Epidemic Timeline



Source: N.Y.S. Dep't of Health, N.Y.S. Ending the Epidemic Timeline (updated Oct. 2020).

Ending the HIV Epidemic in NYS

Science



Community




Political Will





Government/Community Partnership Case Study 1: Sexual Health Clinics

NYC DOHMH Closes City's Largest STD Clinic



NYC Health
Important Notice:
Saturday, March 21, 2015 is the last day to get services at the Chelsea STD Clinic. Starting Tuesday, March 31, services will be available at the Riverside STD Clinic on the Upper West Side.

- The Chelsea STD Clinic at 303 9th Ave. is closing for major, long-term building renovations.
- Services will move to the Riverside STD Clinic, 160 West 100th St. (between Amsterdam and Columbus Aves.), and will be available starting Tuesday, March 31. Hours of operation will not change.
- To find other Health Department STD clinics, visit nyc.gov/health or call 311. For public transportation information, visit www.mta.info/ or call 511.

Aviso importante:
El sábado 21 de marzo de 2015 es el último día para obtener servicios en la clínica de ETS de Chelsea. A partir del martes 31 de marzo, los servicios estarán disponibles en la clínica de ETS de Riverside en Upper West Side.

- La clínica de ETS de Chelsea, ubicada en 303 9th Avenue cerrará por renovaciones mayores de largo plazo en el edificio.
- Los servicios se pasarán a la clínica de ETS de Riverside, 160 West 100th St. (entre Amsterdam Ave. y Columbus Ave.) y estarán disponibles a partir del martes 31 de marzo. El horario de atención será el mismo.
- Para encontrar otras clínicas de ETS del Departamento de Salud, visite nyc.gov/health o llame al 311. Para obtener información sobre el transporte público, visite www.mta.info/ o llame al 511.

重要通知:
2015年3月21日週六是切爾西 STD 診所 (Chelsea STD Clinic) 提供服務的最後一天。從3月31日週二開始，將於上西城的河濱 STD 診所提供服務。

- 位於 303 9th Avenue 的切爾西 STD 診所將因重大的長期大樓整修而關閉。
- 服務地點將遷移至河濱 STD 診所，地址：160 West 100th St. (位於 Amsterdam 與 Columbus Ave. 之間)，將從 3 月 31 日週二開始提供服務。上班時間將維持不變。
- 若要搜尋其他的衛生局 STD 診所，請造訪 nyc.gov/health 或致電 311。關於大眾運輸系統資訊，請造訪 www.mta.info/ 或致電 511。

- In spring 2015, NYC DOHMH announces the closure of the Chelsea STD Clinic, one of its nine STD Clinics offering low-to no-cost STI and HIV testing and STI treatment. At the time:
 - 1 in 42 men who have sex with men (MSM) attending STD Clinics were diagnosed with HIV within a year¹
 - 1 in 15 MSM (1 in 7 Black MSM) diagnosed with anorectal chlamydia and/or gonorrhea in STD Clinics were diagnosed with HIV within a year²
 - 1 in 20 MSM diagnosed with primary or secondary syphilis in NYC were diagnosed with HIV within a year³

Sources: ¹Preeti Pathela et al., *Incidence and Predictors of HIV Infection Among Men Who Have Sex with Men Attending Public Sexually Transmitted Disease Clinics, New York City, 2007-2012*, 21 (5) AIDS & BEHAVIOR 1444-1451 (May 2017); ²Preeti Pathela et al., *HIV Incidence Among Men With and Those Without Sexually Transmitted Rectal Infections: Estimates From Matching Against an HIV Case Registry*, 57 (8) CLINICAL INFECTIOUS DISEASES 1203-1209 (Oct. 2013); ³Preeti Pathela et al., *The High Risk of an HIV Diagnosis Following a Diagnosis of Syphilis: A Population-level Analysis of New York City Men*, 61 (2) CLINICAL INFECTIOUS DISEASES 281-287 (Jul. 2015).

ACT UP Protests STD Clinic Closure



- Following the announcement, ACT UP and Treatment Action Group activists organize a strong response to the clinic closure, mobilizing membership and protesting outside the clinic and City Hall.



ACT UP Protests STD Clinic Closure



EMERGENCY TOWN HALL MEETING

DEBLASIO ADMINISTRATION IGNORES STD/HIV EPIDEMICS IN NYC



In March, the city closed the Chelsea STD clinic with no announcement and no plans to replace the lost testing and treatment capacity. Since then, the number of visits to city STD clinics have decreased by 18%.

Starting in 2010, the Health Department began severely reducing services at the City STD clinics. Since then the number of gonorrhea cases in men citywide increased by more than 40% and the number of syphilis cases in men increased by a third.

Starting in 2011, the City reduced the number of HIV tests that it funds by a third—a loss of over a hundred thousand HIV tests a year.

WE DEMAND THAT THE CITY TAKE OUR SEXUAL HEALTH SERIOUSLY!!!

We are inviting members of the community, the Health Department, City and State Local government to discuss and question these policies on September 1, 2015, at 6:30 PM at the LGBT Community Center on 208 W 43rd St (between 7th Avenue and Greenwich Ave).

FOR MORE INFORMATION VISIT ACTUP.NY.ON.FACEBOOK

EMAIL: JEREMIAH.JOHNSON@TREATMENTACTIONGROUP.ORG Phone: 303 910 9330

ACT UP Protests STD Clinic Closure

- In June 2015, ACT UP sets forth a series of demands calling on NYC DOHMH and the de Blasio administration to:
 - Provide sufficient funding for expanded HIV/STD testing and treatment at neighborhood clinics.
 - Build an inexpensive, prefabricated temporary clinic on the Chelsea STD site that will have capacity equal to the original clinic.
 - Provide funds to expedite the renovations of the shuttered clinic.
 - Appoint a community board to oversee the restoration of testing and prevention services to Chelsea and the renovation of the Chelsea STD Clinic.

Chelsea STD Clinic Reopens as Chelsea Sexual Health Clinic

Join the New York City Health Department for the
GRAND REOPENING
of the
Chelsea Sexual Health Clinic

Thursday
March 15, 2018
2:30 p.m.

Chelsea Health Center
Front Lawn
303 Ninth Avenue
New York, NY

Clinic tours and refreshments to follow.
For more information and to RSVP, please visit: [bit.ly/chelseaclinic](https://www1.nyc.gov/site/doh/about/press/pr2018/pr019-18.page)

NYC
Health

- Following widespread media coverage of the clinic closure and protests, the City announces increased funding to expand and enhance all STD Clinics, including a \$26.3 million overhaul of the Chelsea STD Clinic.
- In March 2018, the Chelsea STD Clinic reopens as the Chelsea Sexual Health Clinic, featuring expanded hours, extensive renovations, and state-of-the-art service enhancements, all City-funded. Services include HIV treatment initiation, PrEP and emergency PEP, and quick start contraception.

Source: Press Release, N.Y.C. Dep't of Health & Mental Hygiene, Chelsea Sexual Health Clinic Reopens After an Extensive Expansion and Modernization of Its Historic Building (Mar. 15, 2018), available at <https://www1.nyc.gov/site/doh/about/press/pr2018/pr019-18.page>.

Chelsea STD Clinic Reopens as Chelsea Sexual Health Clinic





Government/Community Partnership Case Study 2: Securing Minors' Right to Consent to HIV Services

Minors' Right to Consent to HIV Services in NYS

- In 2014 when task force members begin working on a statewide plan to end the HIV epidemic, NYS state law granted minors the right to consent to HIV testing – but not HIV prevention or treatment – without parental/guardian consent or notification.
- Recognizing this as a barrier to ending the epidemic among young people in NYS, task force members include in the NYS Blueprint for Ending the HIV Epidemic a policy recommendation on minors' right to consent to a broader array of HIV and STI services without parental/guardian involvement.

NYS Blueprint for Ending the HIV Epidemic Recommendation on Minors' Right to Consent to HIV Services

Getting to Zero Recommendation #27: Guaranteeing minors the right to consent to HIV and STI treatment, diagnosis, prevention, and prophylaxis . . . including sexual health-related immunization:



“Competent minors, who are already able to consent to both STI and HIV testing without parental consent, also should be guaranteed the right to consent to HIV treatment and ARV prophylaxis. A process or policy must be in place that allows for young adults and youth, including transgender youth, to gain access to HIV and STI treatment, as well as prevention services, such as PrEP and nPEP and immunization for HPV, without parental consent so that confidentiality is preserved. Protections must be in place to ensure that insurance information, such as “explanation of benefits” (EOB) documents, are sent to the patient (i.e. young adult or minor) rather than to the policy holder (i.e. the parents) if that young person is using parental insurance to support HIV treatment or prevention services, such as ARV-P services.”

Source: N.Y.S. DEP'T OF HEALTH, BLUEPRINT FOR ENDING THE EPIDEMIC (Apr. 2015), available at https://www.health.ny.gov/diseases/aids/ending_the_epidemic/docs/blueprint.pdf.

PrEP for Adolescents Statewide Forum

- In November 2015, NYS DOH convenes the first statewide forum on adolescent PrEP implementation featuring researchers, clinical and supportive services providers, government officials, and community members. Attendees discuss key issues and priorities for change to expand access to and implementation of PrEP for adolescents at increased risk for HIV.



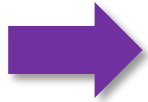
PrEP for Adolescents: Successes, Challenges & Opportunities

A Statewide Forum Hosted by the New York State Department of Health AIDS Institute

NOVEMBER 18, 2015

PrEP for Adolescents Statewide Forum

- Attendees identify five priorities for change to ensure PrEP access and implementation for adolescents:
 - **Update NYS Public Health Law and/or NYS Sanitary Code** to grant minors the right to consent to PrEP without parental/guardian involvement and to protect against unwanted disclosure of sensitive information to parents/guardians;
 - **Increase funding and expand payment options** for PrEP for adolescents;
 - **Frame key issues more effectively**, e.g., consent and payment as health issues, PrEP as a public health issue, HIV prevention as analogous to pregnancy prevention;
 - **Expand training and education** for providers, adolescents, and the community more broadly; and
 - **Expand outreach to adolescents.**



NYS Legislation to Secure Minors' Right to Consent to HIV Services

STATE OF NEW YORK

7683

IN SENATE

May 12, 2016

Introduced by Sen. HANNON -- read twice and ordered printed, and when printed to be committed to the Committee on Health

AN ACT to amend the public health law, in relation to minors' consent to HIV/AIDS testing, treatment and prevention

THE PEOPLE OF THE STATE OF NEW YORK, REPRESENTED IN SENATE AND ASSEMBLY, DO ENACT AS FOLLOWS:

1 Section 1. The public health law is amended by adding a new section
2 2781-b to read as follows:
3 S 2781-B. ACCESS TO HIV/AIDS TESTING, PREVENTION AND TREATMENT FOR
4 MINORS. A HEALTH CARE PROVIDER LICENSED, CERTIFIED OR OTHERWISE AUTHOR-
5 IZED TO PRACTICE UNDER TITLE EIGHT OF THE EDUCATION LAW, ACTING WITHIN
6 HIS OR HER LAWFUL SCOPE OF PRACTICE, MAY, CONSISTENT WITH THIS ARTICLE,
7 TEST, DIAGNOSE, REFER, TREAT AND PRESCRIBE FOR HIV INFECTION, HIV
8 RELATED ILLNESS, AND AIDS, INCLUDING PREVENTATIVE TREATMENT, AN INDIVID-
9 UAL UNDER EIGHTEEN YEARS OF AGE WHO HAS THE CAPACITY TO CONSENT AND WHO
10 HAS BEEN, MAY HAVE BEEN, OR IS AT RISK OF BEING EXPOSED, TO HIV OR AIDS.
11 TESTING, DIAGNOSIS, REFERRAL, TREATMENT AND PRESCRIBING UNDER THIS
12 SECTION MAY BE PROVIDED WITHOUT THE CONSENT OR KNOWLEDGE OF THE PARENT
13 OR GUARDIAN OF THE INDIVIDUAL. HEALTH RECORDS AND OTHER INFORMATION
14 CONCERNING SUCH TESTING, DIAGNOSIS, REFERRAL, TREATMENT OR PRESCRIBING
15 SHALL BE CONFIDENTIAL HIV RELATED INFORMATION AND SHALL NOT BE DISCLOSED
16 EXCEPT AS PROVIDED IN THIS ARTICLE.
17 S 2. This act shall take effect immediately.

- In 2016, NYS Assembly Member Gottfried and NYS Senator Hannon introduce legislation that would amend NYS Public Health Law to allow minors to consent to HIV testing, prevention, care, and treatment services without parental/guardian involvement.
- The bill stalls in committee.

Source: A.10184/S7683, 2015-2016 Leg. Sess. (N.Y. 2016), available at

<https://www.nysenate.gov/legislation/bills/2015/S7683>.

NYS Regulatory Amendments to Secure Minors' Right to Consent to HIV Services

- **Statutory background:** NYS Public Health Law § 23 and its associated regulations ensure that people at risk for or diagnosed with an STI have access to diagnosis and treatment services.
- **Statutory authority:** Pursuant to NYS Public Health Law §§ 225(4), 2304, 2305, and 2311, the NYS Health Commissioner may adopt regulations that list the STIs to which § 23 applies and that establish STI service delivery requirements for local health departments.
- Prior to 2017, § 23.1 of the NYS Sanitary Code (“List of sexually transmissible diseases”) did not include HIV.

NYS Regulatory Amendments to Secure Minors' Right to Consent to HIV Services

- In December 2016, NYS DOH proposes to amend NYS Sanitary Code § 23.1 by adding HIV as a Group B STD, which would:
 - ✓ Require local health department clinics to provide HIV diagnosis, treatment, and prevention services (e.g., emergency PEP, PrEP), directly or by referral;
 - ✓ Allow authorized clinicians (in and outside local health departments' clinics) to administer these services, including to minors without parental/guardian consent or notification; and
 - ✓ Prohibit the release of medical and billing records containing information regarding these services to a minor's parent/guardian without the minor's consent.
- After a public comment period – during which NYC DOHMH and community stakeholders submit comments in support of the proposed rule making – NYS DOH finalizes the regulatory change in April 2017.

NYC DOHMH Trainings on PrEP for Adolescents

- In June 2018, NYC DOHMH begins delivering **trainings to youth providers** affiliated with City and State agencies on PrEP as an HIV prevention strategy for adolescents at increased risk of HIV. The trainings cover the 2017 NYS regulatory amendments securing minors' right to consent to HIV prevention and treatment; HIV surveillance data for young people in NYC; clinical trial data showing PrEP safety and efficacy; and best practices for taking adolescents' sexual history and identifying PrEP candidates.



NYS DOH Guidance on HIV Services, Including for Minors

- **Provider letter and FAQ** on 2015-2017 policy changes related to minors and HPV, STI, and HIV services, and chart on minors' consent to treatment laws (December 2017)
- **Payment guide** for PrEP and emergency PEP (January 2018)
- **HIV testing toolkit** for primary care providers to support routine testing (February 2018)
- **Fact sheet and FAQ** on 2010-2017 policy changes related to HIV testing, reporting, and confidentiality (June 2018)
- **Guidance** for adolescent primary care providers on HIV- and STI-related policies for minors (January 2021)

Sources: N.Y.S. DEP'T OF HEALTH, LETTER ON MINOR CONSENT (Dec. 2017), available at https://www.health.ny.gov/diseases/communicable/std/docs/letter_minor_consent.pdf; N.Y.S. DEP'T OF HEALTH, FAQ: N.Y.S. PUB. HEALTH LAW ART. 23 & TIT. 10, NYCRR § 23, GUIDANCE FOR LOCAL HEALTH DEP'TS & HEALTH CARE PROVIDERS (Dec. 2017), available at https://www.health.ny.gov/diseases/communicable/std/docs/faq_billing_consent.pdf; N.Y.S. DEP'T OF HEALTH, MEDICAL TREATMENT OF MINORS – CONSENT (Jan. 2016); N.Y.S. DEP'T OF HEALTH, PAYMENT OPTIONS FOR ADULTS & ADOLESCENTS FOR PREP (Jan. 2018), available at https://www.health.ny.gov/diseases/aids/general/prep/docs/prep_payment_options.pdf; N.Y.S. DEP'T OF HEALTH, PAYMENT OPTIONS FOR ADULTS & ADOLESCENTS FOR PEP FOLLOWING SEXUAL ASSAULT (Jan. 2018), available at https://www.health.ny.gov/diseases/aids/general/prep/docs/pep_sexual_assault.pdf; N.Y.S. DEP'T OF HEALTH, HIV TESTING TOOLKIT: RESOURCES TO SUPPORT ROUTINE HIV TESTING FOR ADULTS & MINORS (Feb. 2018), available at https://www.health.ny.gov/diseases/aids/providers/testing/docs/testing_toolkit.pdf; N.Y.S. DEP'T OF HEALTH, HIV TESTING, REPORTING, & CONFIDENTIALITY FACT SHEET & FAQ (Jun. 2018), available at https://www.health.ny.gov/diseases/aids/providers/testing/docs/testing_fact_sheet.pdf; N.Y.S. Dep't of Health, HIV Clinical Guidelines Program, Guidance: Adolescent Consent to HIV & STI Treatment & Prevention (Jan. 2021), available at <https://www.hivguidelines.org/hiv-care/adolescent-disclosure-consent/>.

NYS DOH Guidance on HIV Services, Including for Minors

- “You Can Say Yes” campaign (March 2019)



NYS DOH Guidance on HIV Services, Including for Minors



Talking with Adolescents and Young Adults About HIV Consent

About this Booklet:
This booklet was developed to help adolescents understand their rights around consent for HIV treatment, HIV testing, and HIV prevention. It may be helpful for adolescents to review this booklet with someone they trust, like a counselor or health care provider.

HIV Treatment:

Regardless of age, anyone living with HIV can consent to their own HIV treatment.

HIV treatment is:

- Very effective;
- Has few or no side effects;
- May involve taking just one pill once a day.

If you are living with HIV, it is important to get started on medication right away. All studies show that this is the best way to help keep you healthy. The goal is to start treatment the same day, or within 3 days whenever possible.

Having an HIV test is the only way to know for sure if you have HIV. If the test says you have HIV, the provider who ordered the test has to set up an appointment for HIV care with your consent. Find out about all your options. There is a lot of support available in the community. A health care provider or other trusted person can help you find many different types of support providers. You don't have to handle this alone.

NYS DOH Guidance on HIV Services, Including for Minors



HIV Testing:

Regardless of age, you can say yes to an HIV test. You do not need anyone's permission. HIV testing can be as simple as an oral (mouth) swab or fingerprick.

Where can you get HIV testing?

- Your primary care provider's office or pediatrician's office;
- Family planning clinic;
- Local health department;
- Community based organization that offers testing.

Check out www.hivtestny.org for information about HIV testing and to find sites that offer HIV testing near you.

NYS DOH Guidance on HIV Services, Including for Minors



HIV Prevention:

There are many ways to prevent HIV. If you are at risk for HIV or other sexually transmitted infections (STIs) you can make your own decisions about HIV and STI prevention options.

You can prevent HIV and STIs by using a condom every time you have vaginal or anal sex. If you need condoms, you can find them at the NYS Condom Access Program located at <https://www.health.ny.gov/diseases/aids/consumers/condoms/nyscondom.htm> or by emailing NYScondom@health.ny.gov

NYS DOH Guidance on HIV Services, Including for Minors



PrEP

Pre-Exposure Prophylaxis (PrEP) is a medicine prescribed by a health care provider. If you are a candidate for PrEP you can consent to the medication on your own. You have to take the PrEP pill once a day, every day to prevent HIV. Medicaid and most insurance companies cover PrEP but it is good to have help navigating payment options and financial assistance. Contact one of the sites listed here for how to get help with PrEP.

<https://www.health.ny.gov/diseases/aids/general/prep/#prep>

PEP

Post-Exposure Prophylaxis (PEP) is treatment that can prevent you from getting HIV AFTER an exposure if you act quickly. An exposure is having sex without a condom or sharing injection equipment. PEP must be started as soon as possible after the exposure, best if started within 2 hours. It won't work if it is started later than 72 hours (3 days) after the exposure. Exposure to HIV is considered a medical emergency so you should go to a Hospital Emergency Department or NYC Sexual Health Clinic right away.

NYS DOH Guidance on HIV Services, Including for Minors



Can my parents or guardians find out that I've had a medical appointment involving HIV treatment, testing or prevention?

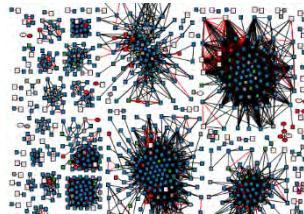
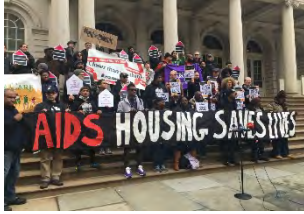
Your medical information about HIV is confidential and cannot be shared, but billing information is something your parent or guardian may receive. This includes young adults aged 18-26 who may still be on their parent's health insurance. As an adolescent or a young adult, you can contact your parent's health insurance and ask for a different mailing address be used for the bill or "explanation of benefits" (EOB). The EOB is a sheet that provides billing codes and general information about what the health care provider treated you for. The EOB does not provide any details about what you discussed with the health care provider. Upon your request, the health insurance company will send that EOB to the new address. However, there is nothing stopping a parent or guardian from requesting an EOB or viewing billing information in their on-line account. Changing the address on the EOB WILL NOT guarantee that your parent or guardian doesn't find out about the bill from your doctor's visit. There are some places (such as Planned Parenthood) that may allow you to pay on a sliding scale without using your parent or guardian's insurance. Check with your provider to see if this is an option for you.

Your medical information about HIV is confidential and cannot be shared, but billing information is something your parent or guardian may receive.



Ending the HIV Epidemic in New York State: Policy Successes

Ending the HIV Epidemic Policy Advocacy: Successes



NYC/NYS joint policy establishing 30% rent cap for HIV/AIDS Services Administration clients ensuring they pay no more than 30% of their monthly income toward rent

2014

NYS legislation expanding HIV data sharing from health departments to health care providers for the purpose of linking clients to care and ensuring ongoing engagement

2014

NYS legislation eliminating written consent for HIV testing (not including in correctional settings, though this followed in 2015)

2014

NYS legislation prohibiting the use of condom possession to establish probable cause for arrest or prosecution for certain prostitution-related offenses

2014

NYS legislation decriminalizing syringe possession for participants of NYS Expanded Syringe Access Program (ESAP) or other medical provider-based programs

2015

Ending the HIV Epidemic Policy Advocacy: Successes



NYS/NYC joint policy expanding HASA program eligibility to include all income-eligible NYC residents diagnosed with HIV (“HASA for All”)

2016



NYS legislation streamlining HIV testing by replacing “informed consent” with the minimum requirement that patients be advised that an HIV test will be performed

2016



NYS legislation expanding HIV testing by removing the upper age limit for offering an HIV test and requiring that testing be offered in certain settings and by certain providers

2016



NYS legislation authorizing nurses to screen for chlamydia, gonorrhea, and syphilis pursuant to a non-patient specific standing order

2016



NYS legislation authorizing pharmacists to dispense 7-day supply of emergency PEP pursuant to a non-patient specific standing order

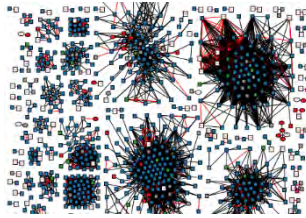
2016

Ending the HIV Epidemic Policy Advocacy: Successes



NYS regulatory amendments securing minors the right to consent to HIV prevention and treatment without parental/ guardian consent or notification

2017



NYS regulatory amendments expanding HIV data sharing from health departments to care coordinators for the purpose of linking clients to care and ensuring ongoing engagement

2017



NYS legislation prohibiting discrimination based on gender identity or expression, and requiring gender identity or expression-related offenses to be treated as hate crimes (“GENDA”)

2019



NYS legislation requiring correctional facilities to provide HIV testing and prevention information and HIV service referrals to inmates upon discharge

2019



NYS legislation requiring hospitals to offer and make available 7-day supply of emergency PEP to adult sexual assault survivors and full 28-day supply to survivors who are minors

2020

Ending the HIV Epidemic Policy Advocacy: Successes



**NYS legislation
repealing the
loitering for the
purpose of
prostitution
criminal offense**

2021

**Manhattan DA
policy ending
prosecutions of
prostitution and
unlicensed
massage cases, and
dismissing
thousands of
prostitution and
prostitution-related
cases**

2021

**NYS legislation
legalizing adult-use
cannabis,
expanding existing
medical marijuana
programs, and
expunging certain
prior convictions
related to
marijuana**

2021

Ending the Epidemic Policy Tracker



ETE POLICY TRACKER


- In December 2019, NYS DOH launches the **Ending the Epidemic (ETE) Policy Tracker** as part of its ETE Dashboard.
- The ETE Policy Tracker highlights legislative, regulatory, and policy activities advancing statewide efforts to end the HIV epidemic. Activities are organized around NYS Blueprint for Ending the HIV Epidemic recommendations.

Ending the Epidemic Policy Tracker

Blueprint Recommendation Timeline

ETE Aim 1	Identify persons with HIV who remain undiagnosed and link them to health care ETE Blueprint Recommendations 1-4	
ETE Aim 2	Link and retain persons diagnosed with HIV in care to maximize virus suppression so they remain healthy and prevent further transmission ETE Blueprint Recommendations 5-10	
ETE Aim 3	Provide access to PrEP for persons who engage in high-risk behaviors to keep them HIV-negative ETE Blueprint Recommendations 11-14	
ETE Aim 4	Recommendations in support of decreasing new infections and disease progression ETE Blueprint Recommendations 15-30	

Getting to Zero Recommendation Timeline

GTZ	ETE Blueprint Getting to Zero Recommendations	
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Ending the Epidemic Policy Tracker

Blueprint Recommendation Timeline



Ending the Epidemic Policy Tracker

Make routine HIV testing truly routine

BP1

2014 2015 2016 2017 2018 2019 2020

New York State Legislation Enacted 2016

Policy **LEGISLATION ENACTED**

Streamlines HIV testing by verbally advising that a test may be performed. Removes upper age limit from the requirement to offer an HIV test

Summary

Chapter 502 of the Laws of 2016 amends New York State Public Health Law (PHL) to streamline routine HIV testing. The amendments require that, at a minimum, the individual be advised that an HIV related test is going to be performed, and that any objection by the individual be noted in the individual's medical record. The legislation also amends PHL to eliminate the existing upper age limit for purposes of offering an HIV related test. New York State Department of Health adopted regulations effective May 17, 2017 to further clarify the intent of this legislation.

Background & Importance to ETE

HIV testing must be made available to more New Yorkers. Half of all people living with diagnosed HIV infection in New York State are age 50 and older, and approximately 200 cases of HIV are diagnosed each year in persons age 60 and older. This bill removes the upper age limit of 64 years on the requirement of offering an HIV test, mandating that an HIV test be offered to all individuals over the age of 13 years. There is no public health basis to justify limiting the offer of an HIV to individuals 64 years and younger, and individuals 65 years and older are exposed to multiple risk factors. In addition, with the advent of new medications, persons over the age of 64 diagnosed with HIV are now able to live average life spans. Early diagnosis and access to treatment remain essential, and this legislation furthers that goal.

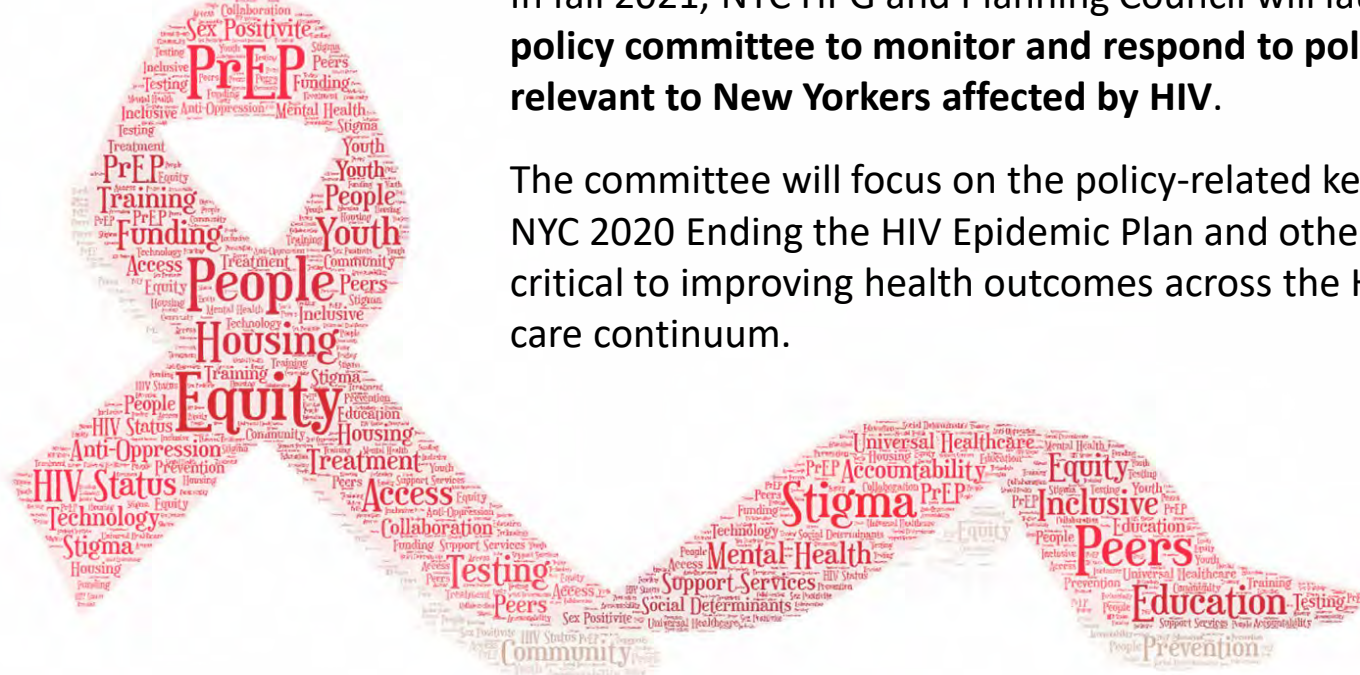
References & Policy Details

- [Chapter 502 of the Laws of 2016](#)
- [10 New York Codes, Rules, and Regulations, Part 63](#)
- [Press Release from Governor Cuomo, December 1, 2016](#)

Next Steps: NYC HPG/Planning Council Joint Policy Committee

In fall 2021, NYC HPG and Planning Council will launch a **joint policy committee to monitor and respond to policy matters relevant to New Yorkers affected by HIV.**

The committee will focus on the policy-related key activities in the NYC 2020 Ending the HIV Epidemic Plan and other policy advocacy critical to improving health outcomes across the HIV status neutral care continuum.



Next Steps: NYC HPG/Planning Council Joint Policy Committee

NYC HPG/Planning Council Joint Policy Committee potential policy advocacy projects may include:

- Expand access to **HIV testing, PrEP, and emergency PEP**, including in nonclinical settings (e.g., pharmacies);
- Strengthen existing HIV and sexual health care **confidentiality protections** and develop new **cost coverage mechanisms for young people**;
- Expand access to comprehensive **sexual health education for young people**;
- Monitor and respond to **health systems policy activity** relevant to New Yorkers with HIV, including Ryan White Part A, Medicaid/Medicare, prescription drug pricing, and New York State of Health Marketplace activity;

(cont.)

Next Steps: NYC HPG/Planning Council Joint Policy Committee

(cont.)

- Expand access to **harm reduction services**, including syringe services programs, medication-assisted treatment, and overdose prevention sites;
- Expand access to HIV and sexual health services in **correctional settings** while also supporting initiatives that combat mass incarceration;
- Support a shift in the collective approach to consensual **sex work**, moving away from criminalization and stigmatization, and toward meeting the health and safety needs of people who exchange sex;
- Address **HIV criminalization**, including by educating criminal justice stakeholders on the public health harms of such policies;

(cont.)

Next Steps: NYC HPG/Planning Council Joint Policy Committee

(cont.)

- Build the capacity of the **HIV workforce**, including peer workers, to deliver HIV services with fair compensation;
- Advocate for the FDA to eliminate its time-based **blood donation deferral policy** based on the sexual orientation or gender of potential donors' sexual partners; and
- Develop **collaborations, partnerships, and policy changes with City and State agencies** to address the mental and behavioral health; emergency, transitional, supportive, and permanent housing; employment; public assistance; and legal services needs of New Yorkers affected by HIV.

An aerial photograph of New York City, showing the dense urban landscape and the Manhattan skyline. The image is overlaid with a semi-transparent blue filter. The text "The Denver Principles" is centered in the middle of the image.

The Denver Principles

The Denver Principles

In 1983, AIDS activists took the stage at the National Lesbian and Gay Health Conference in Denver to demand recognition – not as victims or patients, but as “People with AIDS.” Their recommendations and their list of rights of people with AIDS became known as the Denver Principles.



Source: UNAIDS, The Denver Principles (1983) (last accessed Jul. 21, 2021), available at https://data.unaids.org/pub/externaldocument/2007/gipa1983denverprinciples_en.pdf; Nell London, *The Founding Principles of AIDS Activism Were Created Not in New York or San Francisco, But Denver*, CPR (Aug. 29, 2018), available at <https://www.cpr.org/show-segment/the-founding-principles-of-aids-activism-were-created-not-in-new-york-or-san-francisco-but-denver/>.

Selections from The Denver Principles

RECOMMENDATIONS FOR ALL PEOPLE

1. Support us in our struggle against those who would fire us from our jobs, evict us from our homes, refuse to touch us or separate us from our loved ones, our community or our peers, since available evidence does not support the view that AIDS can be spread by casual, social contact.
2. Not scapegoat people with AIDS, blame us for the epidemic or generalize about our lifestyles.

Selections from The Denver Principles

RECOMMENDATIONS FOR PEOPLE WITH AIDS

1. Form caucuses to choose their own representatives, to deal with the media, to choose their own agenda and to plan their own strategies.
2. Be involved at every level of decision-making and specifically serve on the boards of directors of provider organizations.
3. Be included in all AIDS forums with equal credibility as other participants, to share their own experiences and knowledge.

Selections from The Denver Principles

RIGHTS OF PEOPLE WITH AIDS

1. To as full and satisfying sexual and emotional lives as anyone else.
2. To quality medical treatment and quality social service provision without discrimination of any form including sexual orientation, gender, diagnosis, economic status or race.
3. To full explanations of all medical procedures and risks, to choose or refuse their treatment modalities, to refuse to participate in research without jeopardizing their treatment and to make informed decisions about their lives.
4. To privacy, to confidentiality of medical records, to human respect and to choose who their significant others are.
5. To die – and to LIVE – in dignity.

An aerial photograph of New York City, showing the dense urban landscape and the Manhattan skyline. The image is overlaid with a blue and purple color gradient. The word "Discussion" is centered in the middle of the image in white text.

Discussion

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