

January 31, 2024

The Honorable Liz Krueger
Chair, Committee on Finance
New York State Senate
416 Capitol Building
Albany, NY 12247

The Honorable Helene E. Weinstein
Chair, Committee on Ways and Means
New York State Assembly
711-A Legislative Office Building
Albany, NY 12248

The Honorable Gustavo Rivera
Chair, Committee on Health
New York State Senate
502C Capitol Building
Albany, NY 12247

The Honorable Amy Paulin
Chair, Committee on Health
New York State Assembly
823 Legislative Office Building
Albany, NY 12248

Dear Chair Krueger, Chair Weinstein, Chair Rivera, and Chair Paulin,

As public health experts; public defenders; civil rights, LGBTQ, and immigrants' organizations; health care providers; and people living with HIV, we urge you to remove Section 4 of Part T from the Executive Health and Mental Hygiene (HMH) FY2025 Article VII legislation.

While New York has made considerable progress in reducing the prevalence of HIV over the last decade,¹ the COVID-19 pandemic exacerbated hurdles to HIV prevention, testing, and treatment. Moreover, New York continues to see stark disparities in HIV's impact with Black, Indigenous, and other New Yorkers of color, as well as transgender New Yorkers and young men who have sex with men, bearing the brunt of the epidemic.² The undersigned organizations embrace the goal of Ending the Epidemic. Unfortunately, Section 4 of HMH Part T, notwithstanding the good intentions of those proposing it, undermines this goal and poses serious harm to many of those whom this proposal targets, particularly undocumented immigrants and others whose lives are bound up with government agencies that regulate their medical care choices, parenting, and other very personal issues.

Section 4 of HMH Part T proposes to eliminate effective notice and consent for an individual who is about to be tested for HIV. It also proposes to remove the requirement that patients be offered the opportunity to anonymously test for HIV, if that is the option that is safest for them. Instead, providers would be permitted to simply notify patients of HIV testing with posted placards in their offices and waiting rooms or buried in the fine print of lengthy consent forms.

¹ New York State Budget and Policy Priorities NYS Fiscal Year 2025, Ending the Epidemic 2 (Nov. 2023).

² *Id.*

HIV Testing Without Effective Notice or Consent Endangers Patients

Notices on the walls of busy clinics, waiting rooms, and emergency departments or hidden in a boilerplate consent form³ do not constitute effective notice to a person presenting for care that they must assert an objection at some point to avoid being tested for HIV. These approaches ignore the fact that many of those seeking care do not have functional vision, cannot read, do not speak English or any of the other languages a notice might be posted in or a consent form might be printed in, or have mental or cognitive impairments – and that they often present in the kind of physical distress from acute pain or illness that precludes simultaneously understanding that at some unidentified point they must object or they will be tested for HIV.

The proposal also ignores the reality that for those who are undocumented, testing for HIV while being treated for an acute health care need may place their ability to stay in or return to this country in peril.⁴ It ignores the all too frequent scenario of people in mental health crisis, as well as people of color, who are brought into an ER for injuries sustained after “resisting arrest”; with this proposal, arresting officers may have access to HIV test results, which can turn a mishandled arrest into a felony charge for the arrested individual. Similarly, when an abusive partner brings a domestic violence survivor to the ER, that abusive partner may get access to the survivor’s HIV test results, increasing the survivor’s risk of further abuse.⁵

Removing Effective Notice May Not Result in More Testing and Will Not Increase Engagement in Care Needed to Prevent Further HIV Transmission

Strikingly, this proposal is being advanced with no data to support it. While there is unquestionably an ongoing problem of late HIV diagnoses and dual diagnoses in New York State, proponents of eliminating notice and consent for HIV testing offer no data to suggest that eliminating notice will solve that problem. In fact, it is unclear whether people who are dually diagnosed have previously had contact with medical providers, have been offered and declined testing in the past, or have never been offered HIV testing at all in violation of

³ Cf. Alexis C. Madrigal, *Reading the Privacy Policies You Encounter in a Year Would Take 76 Work Days*, THE ATLANTIC, Mar. 1, 2012, <https://www.theatlantic.com/technology/archive/2012/03/reading-the-privacy-policies-you-encounter-in-a-year-would-take-76-work-days/253851/>.

⁴ See “HIV Criminalization in California: What We Know,” The Williams Institute, *available at* <https://williamsinstitute.law.ucla.edu/wp-content/uploads/HIV-Criminalization-What-We-Know-2017.pdf> (“Based on the data available, it did appear that there were some individuals who had deportation proceedings brought immediately after an HIV-specific criminal incident.”).

⁵ See Tami Sullivan, *The Intersection of Intimate Partner Violence and HIV: Detection, Disclosure, Discussion, and Implications for Treatment Adherence*, 27 TOP ANTIVIR. MED. 84 – 87 (2019) (Twenty-four percent of women experience abuse by their partners after their partner learns their HIV status).

existing New York law.⁶

Where providers are already violating New York State law by declining to offer HIV testing, it is hard to imagine that they will engage in conversations with patients who test positive about the meanings of those results, the benefits of treatment, and how to connect with appropriate providers and treatment options.

Moreover, testing without notice, consent, or transparency threatens to erode trust between patients and medical providers, especially given the HIV stigma and discrimination that pervade both the medical and the legal establishments.⁷ In fact, rather than increasing access to HIV treatment, perversely testing people without their knowledge or consent risks alienating them from pursuing further care. Patients may think twice about again seeking medical treatment, including HIV treatment, for fear that they will be subjected to further testing or interventions without their notice and consent.

The concern is particularly acute among Black, Indigenous, and other communities of color, who have long suffered from medical mistreatment. Many, particularly in the Black community, remember the Tuskegee syphilis study – when, in the 1930s, the U.S. government studied the trajectory of untreated syphilis in hundreds of Black men, both concealing the nature of their research and withholding effective treatment after one had been identified.⁸ Indigenous Americans, too, have survived “significant unethical research and medical care” since colonization.⁹ And, Latinx New Yorkers remember that between the 1930s and the 1970s, approximately one-third of Puerto Rican women and girls were forcibly sterilized.¹⁰ This history feels strikingly present as immigrants detained in ICE facilities in Georgia as recently as 2020 reported forced hysterectomies.¹¹

⁶ N.Y. Pub. Health § 2881-a (McKinney) (requiring that medical providers offer testing to all individuals over thirteen years old with limited exceptions).

⁷ See e.g., McAllister, Carolyn, Susan Reif, and Elena Wilson, *Perceptions and Impact of HIV Stigma Among High Risk Populations in the US Deep South*, J. OF HIV AND AIDS (April 6, 2018), available at

<https://www.hivlawandpolicy.org/sites/default/files/Perceptions%20and%20Impact%20of%20HIV%20Stigma%20among%20High%20Risk%20Populations%20in%20the%20US%20Deep%20South.pdf>.

⁸ Peter Jamison, *Anti-vaccination leaders fuel [B]lack mistrust of medical establishment as covid-19 kills people of color*, WASH. PO., July 17, 2020, https://www.washingtonpost.com/dc-md-va/2020/07/17/black-anti-vaccine-coronavirus-tuskegee-syphilis/?hpid=hp_hp-banner-main_black-antivax-940am%3Ahomepage%2Fstory-ans.

⁹ See Felicia Schanche Hodge, *No Meaningful Apology for American Indian Unethical Research Abuses*, 22 ETHICS & BEHAVIOR 431 (2012).

¹⁰ Katherine Andrews, *The Dark History of Forced Sterilization of Latina Women*, UNIV. OF PITTSBURGH, Oct. 30, 2017, <https://www.panoramas.pitt.edu/health-and-society/dark-history-forced-sterilization-latina-women>.

¹¹ Caitlin Dickerson, Seth Freed Wessler, & Miriam Jordan, *Immigrants Say They Were Pressured Into Unneeded Surgeries*, N.Y. TIMES, Sept. 29, 2020, <https://www.nytimes.com/2020/09/29/us/ice-hysterectomies-surgeries-georgia.html>.

New York has recognized time and again during the COVID-19 pandemic that people will not seek health care if they worry that it will lead to criminalization or negative immigration consequences and that forcefully imposing testing or treatment on individuals can perversely drive them away from health care settings. It is for those reasons that New York enacted contact tracing confidentiality in 2020¹² and vaccine confidentiality in 2022.¹³ The same rationale animates the laudable effort, also reflected in the Governor's HMM Part T, to repeal New York's STI and HIV criminalization law, Public Health Law § 2307.

Informed Consent Is Standard for Disease-Specific Medical Testing

Unfortunately, HIV stigma – and collateral consequences associated with HIV – persist in New York and across the U.S. Therefore, testing for HIV is categorically different from basic screening tests that may be conducted without explicit notice. Routine labs like a complete blood count or a comprehensive metabolic panel are general and astigmatized; whereas, an HIV test is very specific and should be treated no differently from other very specific screening tests for which specific notice and consent is required, such as those for prostate or breast cancer.

Fully informing patients of their rights need take little or no time away from other treatment, nor do such conversations need to be fraught with discomfort. Indeed, an informed patient is more engaged in, and therefore takes more responsibility for, maintaining their health.¹⁴ Busy, successful medical providers repeatedly report that such notice and consent can be accomplished in mere minutes and improves relationships between patients and providers. To the extent that medical providers avoid that conversation because they are uncomfortable discussing HIV testing and treatment, think it is a waste of scarce time to give options to people they consider at significant risk of HIV, or view the conversation as uncompensated time, the solution is improved training in best practices and to ensure that Medicaid and private insurance cover the conversation, not a curtailing of patients' rights to make medical decisions for themselves. As a long-time adolescent HIV care provider at a busy Brooklyn clinic observed:

It is a kind of bias to assume that there is no time to ask a few simple questions and document verbal consent, especially if the provider perceives the patient to be at risk due to their socioeconomic and ethnic background. Assumptions are being made that all Black and Brown people who are poor are at higher risk for HIV, and so we should just go ahead and give them an HIV test as a "routine" test without a brief, even perfunctory discussion of risk and request for consent. But this simple discussion can be accomplished in under two minutes for most people and

¹² N.Y. Pub. Health §§ 2180 – 82 (McKinney).

¹³ N.Y. Pub. Health §§ 2169, 2180, 2183 (McKinney).

¹⁴ See Julia James, *Patient Engagement*, HEALTH AFFAIRS, Feb. 14, 2013, <https://www.healthaffairs.org/doi/10.1377/hpb20130214.898775/>.

individuals who do have higher risk can be engaged in a longer conversation, if appropriate.¹⁵

For all of these reasons, we urge the state to remove the proposed changes to Public Health Law §§ 2781(1) and (4) from Section 4 of the Executive HMM Part T proposal.

Thank you for your consideration,

The Bronx Defenders
Brooklyn Defender Services
Center for Health Law and Policy Innovation of Harvard Law School
Center for HIV Law and Policy (CHLP)
Electronic Frontier Foundation
HEAT (Health & Education Alternatives for Teens)
Immigrant Defense Project
Lambda Legal
Legal Action Center
The Legal Aid Society
Neighborhood Defender Service of Harlem
New York Civil Liberties Union
Pregnancy Justice
SERO Project
SMART: Sisterhood Mobilized for AIDS/HIV Research & Treatment
Surveillance Resistance Lab

and

Jeffrey Birnbaum, MD, MPH
Associate Professor of Pediatrics and Public Health, SUNY Downstate Medical Center
Executive Director, HEAT (Health & Education Alternatives for Teens)

Catherine Hanssens, JD
Founder/Emerita, CHLP
Sexual/Reproductive Health Rights and Criminalization Consultant

CC. Members of the New York State Senate Committees on Finance and Health
Members of the New York State Assembly Committees on Ways and Means and Health

¹⁵ See Letter from Jacob Schneider, Staff Attorney, & Catherine Hanssens, Executive Director, The Center for HIV Law & Policy, et al. to Brad Hoylman, New York State Senator (May 22, 2019) (on file with author).