

2023 – 2024 Legislative Memorandum

**Subject: Relates to notice of certain medical options and to communication with the person being tested prior to HIV related testing.
A.8475 (Paulin) / S.7809 (Hoylman-Sigal)**

Position: OPPOSE

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 NYCLU embraces the goal of Ending the Epidemic. Unfortunately, A.8475 (Paulin)/S.7809 (Hoylman-Sigal) undermines this goal.

A.8475/S.7809 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.

Because being tested for HIV without one’s knowledge or consent can lead to collateral immigration, domestic violence, and criminal law consequences, and because there is no reason to believe that nonconsensual HIV testing will channel people into treatment and some evidence to suggest that it will alienate people from accessing health care, the NYCLU opposes A.8475/S.7809 and urges the legislature to reject it.

Most patients do not read informed consent forms at medical offices.³ Notices on the walls of busy clinics, waiting rooms, and emergency departments do not constitute effective notice to a person presenting for care that they must assert an objection at some point to avoid being

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

² *Id.*

³ *E.g.* Mehmet Ozgur Ozhan et. al, *Do the Patients Read the Informed Consent?*, 31 BALKAN MED. J. 132 – 36 (2014).

tested for HIV. This approach ignores 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 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.

A.8475/S.7809 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

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 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 many patients will have experienced both in the medical and the legal establishments.⁷ In fact, rather than increasing access to HIV treatment, perversely testing people without their

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).

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>.

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

The legislature 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 this legislature enacted contact tracing confidentiality in 2020¹² and vaccine confidentiality in 2022.¹³ The NYCLU urges the legislature to adhere to these values and public health goals by rejecting A.8475/S.7809.

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>.

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

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