



TESTIMONY OF THE LEGAL ACTION CENTER

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The Legal Action Center is a non-profit law and policy organization that fights discrimination, builds health equity, and restores opportunity for people with substance use disorders, arrest and conviction records, and HIV and AIDS. LAC works to combat the stigma and prejudice that keep these individuals out of the mainstream of society, helping people reclaim their lives, maintain their dignity, and participate fully in society as productive, responsible citizens.

LAC has a long history fighting for people with HIV/AIDS. We represent people whose HIV status has been disclosed without their consent and in violation of State law. These disclosures can also have devastating and discriminatory consequences for people and their families, workplaces, even criminal consequences.

LAC was one of the founders of and continues to co-chair, coordinate and staff the Coalition for Whole Health, a national coalition bringing together advocates from the mental health and substance use disorder fields. The Coalition played a key role in advocating for passage of the federal Mental Health Parity and Addiction Equity Act (Parity Act) and ensuring that parity for behavioral health services was a key component of the Affordable Care Act.

Pre-test notification of an HIV test

LAC opposes the provision in the Executive's Health and Mental Hygiene Article VII Budget Legislation found in Part T that would eliminate the requirement for providers to orally advise an individual before they will be tested for HIV. Further, it is unclear that it will even lead to more testing.

Testing individuals for HIV without their knowledge is inconsistent with CDC and WHO recommendations and may violate the code of ethics for nursing. While some providers may continue to notify people that they will be tested, the removal of the notification requirement means that people will be tested without their knowledge. Indeed, the rationale behind the proposed change is that requiring providers to notify people is a barrier to testing. However,

elimination of the offer is not in line with recommendations from the CDC,¹ the WHO² and authorities in other nations.³

Depriving patients of the right to autonomy over critical medical decision-making about a highly stigmatizing illness which can lead to domestic violence and social ostracism undermines patient-centered care. All individuals should be allowed to make decisions about their own medical care. Furthermore, even though medical advances have made HIV a treatable and preventable chronic disease, enormous stigma remains, including within the medical community. We continue to represent clients who are discriminated against due to their HIV status.⁴ This proposal runs against an increasing move towards patient-centered care, based in part on the concept of patient empowerment. Instead, the proposal goes in the opposite direction, by representing a continuation of the historic paternalistic attitude of medical professionals towards patients.

Eliminating a verbal HIV test notice will eliminate the mandatory test offer and the right to object will be meaningless. Removing a requirement that providers verbally inform the patient of an HIV test would essentially remove a mandatory test offer because one cannot offer a test without notifying the individual of the test. If a person is not adequately advised that they are being tested, they are essentially not being offered a test. And secondly, while the Executive Budget retains the right to object to testing, this right will be meaningless to those who are unaware that they will be tested.

Removal of HIV testing notice could lead to more confidentiality breaches. People who are HIV tested without their knowledge may have friends or family present when the test results are delivered. Had they known they were undergoing an HIV test, they could choose whether to

¹ Current NYS requirements are in line with the most recent CDC recommendations from 2006 which recommended that “A process of communication between patient and provider through which an informed patient can choose whether to undergo HIV testing or decline to do so. Elements of informed consent typically include providing oral or written information regarding HIV, the risks and benefits of testing, the implications of HIV test results, how test results will be communicated, and the opportunity to ask questions.” (CDC Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-Care Settings <https://www.cdc.gov/mmwr/preview/mmwrhtml/rr5514a1.htm>)

² In 2021, the WHO continued to recommend in their updated Guiding Principles of Consolidated Guidelines on HIV Testing Services that HIV testing must include Pre-test information including an explanation of issues and services and an opportunity to ask questions. See page 13 in Guidelines: <https://www.who.int/publications/i/item/9789240031593>

³ The UK General Medical Council instructed doctors that when “undertaking an investigation or providing treatment [for any condition], it is your responsibility to discuss it with the patient.” (General Medical Council, “Consent: patients and doctors making decisions together” (2008) https://www.gmc-uk.org/-/media/documents/consent---english-0617_pdf-48903482.pdf)

⁴ Dermatologist refused to treat a man with HIV and required him to come to the office after hours: <https://www.lac.org/resource/doe-v-lefkowitz-et-al>

have friends or family present for delivery of the results. Article 27F prohibits health care providers from disclosing HIV-related information to friends/family without written patient consent, but LAC regularly receives calls from patients whose health care providers disclosed their HIV status without their consent to friends and family who were present. Secondly, the recently implemented federal Information Blocking Rule requires test results to be immediately uploaded into patient portals and patients usually receive an email notification. Even though Article 27F prohibits it, positive HIV test results may show up in a portal. This could be surprising to someone who didn't know they were tested. There are also many situations where people other than the patient have access to the patient portal, like parents with access to a minor's portal. If a patient was unaware they were tested for HIV, those results may be visible to anyone with access to their patient portal.

Testing without knowledge could harm relationships between individuals and providers and increase health disparities. HIV testing without knowledge will likely be more common in poor communities and communities of color which have long histories of being subject to medical experimentation and procedures without consent or knowledge. For decades, messaging to these communities has been about the right to informed, voluntary HIV testing. Removing this requirement could cause a feeling of betrayal and harm trust between communities and providers. This loss of trust and ongoing stigma could result in people being lost to care after a test and a reluctance to seek medical care generally. There is also real concern about language access where information about HIV testing is only posted, as well as limited access for people with visual impairments or other disabilities. We have also heard that a justification for this policy change is the discomfort providers feel in offering a test and the burden of entering it into a patient chart. But being able to deal with sensitive information and having the time necessary to provide information is critical in the event of a positive test result. Poor communication of the results could have significant emotional consequences which could in turn impact whether someone remains in care.

Repeal Section 2307 of the Public Health Law

LAC strongly supports the repeal of Public Health Law 2307 (PHL 2307), a New York law that makes it a crime for a person who knows they currently have a sexually transmitted infection (including HIV) to have sexual intercourse with another person. We urge the legislature to go even further by adopting the provisions in the REPEAL STI Discrimination ACT (REPEAL Act).⁵ The REPEAL Act amends New York State criminal statutes to those living with STIs who have sex will not be criminalized solely based on their health status.

⁵ S4603/A3347 [NY State Senate Bill 2023-S4603](#)

PHL 2307 disincentivizes testing for some diseases as knowledge of one's status could lead to prosecution. There is no current research available that shows that laws criminalizing diseases such as STIs and HIV have an effect on transmission rates or encourage disclosure of one's status. It also disproportionately impacts communities of color, especially LGBTQ+ communities of color. The law reflects oversized fear, stereotyping of those affected by the disease, and assignment of blame to already-marginalized members of society. It also has an outsize impact on victims of intimate partner violence who have to choose between being charged with a crime for not disclosing their status to their partner or opening themselves up to more violence if they do disclose their status.

PHL 2307 is a harmful relic of the past and at odds with modern public health policy. In 2022, almost 80% of New Yorkers living with diagnosed HIV were virally suppressed.⁶ This means that most people living with HIV are virtually incapable of transmitting HIV to another person via sexual contact, yet those people could still be criminalized for having sex.

The American Medical Association, the Center for Disease Control, the White House and the United Nations all oppose health status criminalization.⁷ Repealing PHL 2307 partially addresses this problem, but to fully eliminate the possibility for people to be criminalized for their health status, the broader REPEAL Act must be adopted. It also automatically clears prior convictions for those criminalized by PHL 2307 in the past.

The REPEAL Act goes further than simply repealing PHL 2307 because individuals can currently be charged with other crimes for due to their health status in New York, and simply eliminating PHL 2307 will not address that.

Raise Reimbursement Rates for Substance Use Disorder Services

We commend Governor Hochul for recognizing the widespread workforce shortage in all health sectors, and in particular in the mental health (MH) and substance use disorder (SUD) workforce where reimbursement rates are chronically low, workload is high, and stress leads to burnout and turnover. However, amid the immense overdose crisis gripping our state, it is important to address Medicaid reimbursement rates for providers of addiction services. In particular, hospital-based addiction services are reimbursed at excessively low rates throughout the state, especially when compared to commercial rates in those facilities. However, it is much more likely for Medicaid patients to receive care in hospitals than their commercially insured counterparts. This means that addiction services are likely operating at a loss and there is little

⁶ Data Source: NYS HIV Surveillance System. NYS/DOH/AI Bureau of HIV/AIDS Epidemiology. Data reported as of March 2023.

⁷ See: <https://www.poz.com/article/criminalization-ama-25757-3651> and <https://www.undp.org/publications/undp-and-unaid-policy-brief-criminalization-hiv-transmission>

incentive for hospitals to support the expansion of these services because the reimbursement rates do not even cover the costs. It also might be a parity violation, where reimbursement rates for hospital-based addiction services are not being set in a comparable process and applied no more stringently than for similar medical service reimbursement rates. The wide disparities in Medicaid rates between some medical services and addiction services at many hospitals would indicate that is the case.

Medicaid Reentry Section 1115 Demonstration Opportunity

We were troubled to see that the recently approved Medicaid 1115 Waiver for New York did not include the criminal justice waiver to use Medicaid dollars to provide services to people before they are released from incarceration. We believe this is a missed opportunity to ensure people leaving incarceration with opioid and other substance use disorders, mental health and other health problems are appropriately assessed and connected to needed care. People with criminal legal system involvement often have a very high need for health care services and due to racism in all of our systems, Black and brown people are disproportionately represented in our jails and prisons. Care in these facilities is poor, and we had hoped New York would continue their stated commitment to prioritize financing certain health services for Medicaid-eligible beneficiaries who are preparing to return home from incarceration to help eliminate these health disparities. New York already applied for this reentry opportunity in previous years, and CMS issued guidance in April⁸ encouraging states to reapply. Yet, we now find ourselves behind several other states who have applied to implement this critical policy. We urge the legislature to work with the Executive to ensure that a waiver application is submitted soon, as many other states are rushing to do.

We thank you for the opportunity to submit this testimony and look forward to working with you on these important issues.

⁸ <https://www.cms.gov/newsroom/press-releases/hhs-releases-new-guidance-encourage-states-apply-new-medicaid-reentry-section-1115-demonstration>