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March 26, 2019

The Honorable Richard Gottfried
LOB 822
Albany, NY 12248

RE: Opposition to Proposed Bill to Eliminate Patient Autonomy in HIV Testing Decisions

Dear Assemblymember Gottfried:

As people living with HIV (PLHIV), their advocates and health care providers, we are writing to express our serious concerns with the proposal to completely eliminate consent and even effective notice to an individual that they are about to be tested for HIV.[1] In a state that has prioritized evidence-based approaches to HIV care, it is striking that this proposal is being advanced with no data to support it. Current law requires hospital care providers to offer HIV testing to those who present for care. Rather than push for concrete measures to enforce the law in institutions where doctors are failing to offer or support HIV testing, the proposal seeks to address the serious problem of late HIV diagnoses by eliminating any requirement that a provider speak with an individual before testing them.

This proposal has been advanced without real transparency, including a broad opportunity for the people who will live with its consequences to weigh in on such a serious change of law and practice. There is real urgency to addressing the ongoing problem of late diagnoses and treatment of those living with HIV in New York State.[2] That urgency requires that we take a closer look at those cases and places where late diagnoses continue to occur and address the real causes rather than further dilute patient autonomy for people affected by HIV.

The proposal would remove the provisions of New York's Public Health Law that currently require a medical provider to provide direct notice of the test—including informing the patient about several crucial medical facts as well as the patient's rights—and to either decide not to test or to give verbal consent. The rationale for testing, along with limited HIV education,

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[1] *See* "Letter from 'Coalition for Removal of all Consent and Notification Requirements for HIV Testing' to Assemblymember Richard Gottfried," dated June 4, 2018, (hereinafter "Letter from Coalition for Removal").

[2] It is notable that, while this may be a public health priority for the state, it is unclear whether the New York City Department of Health perceives this to be an issue in New York.

would be provided to the individual after testing is conducted.[3]

We embrace the goal of Ending the Epidemic, and we do not question the good intentions of those proposing this radical exemption to modern principles of patient autonomy in medical decision-making. Our concern is not with motives but with consequences. We do not believe that eliminating the legal requirement that HIV testing be voluntary and consensual is the appropriate response to proponents' frustration with persistent provider refusal to follow state law, encouraging patients to test for HIV.

Our primary objection is the knowledge that this proposal will not get us any closer to ending the epidemic, and in fact 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 choice, parenting and other very personal issues. The proposal also is in conflict with state and federal law protecting the rights of New York health care patients and people living with disabilities.

There Is No Evidence that the Eliminating Notice of HIV Testing Will Solve the Problem of Dual Diagnosis

In support of the proposed elimination of notice of HIV testing, proponents cite high rates of dual diagnosis (diagnosis of HIV and AIDS at the same time) in upstate New York. However, they offer no data suggesting that eliminating notice of HIV testing will solve that problem. In fact, it is unclear whether persons who are dually-diagnosed have not previously had substantial contact with medical providers, have been offered and declined HIV testing in the past, or have not been offered HIV testing at all. If such persons have not been offered HIV testing at all—in violation of the Public Health Law[4]—it is unclear that advocates or public health officials have made any effort to enforce the mandatory offer of HIV testing, though officials say that it would be possible for the state to identify which doctors are not routinely offering HIV tests. The state must quickly study and answer these questions, and undertake common sense public health measures like enforcing the current law's mandatory offer requirement, before so drastically revising the HIV testing law to eliminate notice and verbal consent.

Crucial Provisions of the HIV Testing Law Depend on Notice of Testing

Eliminating the notice and consent requirement of the HIV testing law will have a dramatic effect on the structure of the statute, including rendering it internally inconsistent and ineffective. Other crucial sections of the law, including the mandatory offer of testing[5] and the requirement that anonymous testing be made available[6], depend on patients receiving effective notice of testing.

Notably, if patients are not effectively provided notice of testing, it will not be possible for them to opt out or opt in for anonymous testing. The importance of providing patients the option to test anonymously as a public health measure cannot be overstated in a context in which many patients fear the stigma and legal consequences of HIV testing. Such collateral consequences include evolving legal issues such as changes in immigration enforcement and discretionary policies under President Donald Trump.

Informed Consent Is Standard for Disease-Specific Medical Testing

A group of CEOs from large HIV medical providers and service organizations argue in support of their proposal that "the law still poses logistical barriers that don't exist for any

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[3] Pub. Health § 2781.

[4] Pub. Health § 2881-a requires that medical providers offer testing to all individuals over thirteen years old with limited exceptions.

[5] Pub. Health § 2881-a.

[6] Pub. Health § 2881(4).

other screening test—including Hepatitis C—thus preventing HIV testing from being implemented routinely."[7] This is patently untrue. It is not common practice throughout New York or the rest of the country to test an individual for a serious chronic disease without a prior explanation, nor does it conform with professional standards or practices in this area.[8]

In fact, two significant fictions propagated to support a return to practices popular until the latter part of the last century are that patient-centered care and communications with clients pose a significant barrier to effective diagnosis and treatment; and that it is standard practice to do a wide array of tests unrelated to a patient's symptoms without informing the patient what they are being tested for and why.

There are certain basic screening tests done to assess overall health, but most providers will explain even these before testing a patient; an informed patient is more engaged in, and therefore takes more responsibility for, maintaining their health.[9] [10] Moreover testing for HIV is categorically different than basic screening tests. 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, 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. 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, or think it is a waste of scarce time to give options to people they consider at significant risk of HIV, the solution is improved training in best practices, not a curtailing of patients' rights to make medical decisions for themselves.[11]

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

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[7] *See* Letter from Coalition for Removal.

[8] Advocates for elimination of patient choice insist that NY law currently allows exactly this type of procedure for diagnosing Hepatitis C (HCV). To the contrary, and as posted on the NYS DOH website:
A hepatitis C screening test must be offered to every individual born between 1945 and 1965 receiving health services as an inpatient or a hospital, or receiving primary care services in the outpatient department of hospital, or in a freestanding diagnostic and treatment center or from a physician, physician assistant, or nurse practitioner providing primary care.
If an individual accepts the offer of the hepatitis C screening test and the screening test is reactive, the health care provider must offer the individual follow-up health care or refer the individual to a health care provider who can provide follow-up health care. The follow-up health care must include a hepatitis C diagnostic test.
The offer of testing must be culturally and linguistically appropriate.
See https://www.health.ny.gov/diseases/communicable/hepatitis/hepatitis_c/rapid_antibody_testing/faqs.htm; https://cdn.hivguidelines.org/wp-content/uploads/20190228144841/NYSDOH-AI-Treatment-of-Chronic-HCV-with-Direct-Acting-Antivirals-Guideline-PDF_2-28-2019_HG.pdf

[9] *See* American Medical Association Code of Medical Ethics Opinion 2.1.1 *available at* https://www.ama-assn.org/delivering-care/ethics/informed-consent.

[10] Brach, Cindy, *Even in an Emergency, Doctors Must Make Informed Consent An Informed Choice*, Health Aff (Millwood) 35(4) 739 (2016) ("There is a growing expectation that doctors should be effective communicators. Medical schools have begun to teach communication skills, especially since the United States Medical Licensing Examination started testing those skills with the use of simulated patients in 2004, and the communication skills component of the exam was enhanced in 2012").

[11] Indeed, this proposal would not solve any issues of provider or patient discomfort at all, but merely unproductively kick these important conversations down the road and keep patients in the dark about their rights and options at a crucial stage in engagement.

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

Both New York Law and Medical Ethics Require Informed Consent

The proposed change is premised on a faulty assumption that if not for the HIV-specific testing law, providers would be able to engage in testing without notice and consent. In fact, the value of respecting a patient's dignity and right to make affirmative decisions with respect to medical treatment, medical testing, and disclosure of sensitive information is so important that it is enshrined in the Patient's Bill of Rights that New York's Public Health Law requires that every medical facility post.[12] The Patient's Bill of Rights makes it clear that patients are entitled to "receive complete information about your diagnosis, treatment, and prognosis."[13] A patient also has the absolute right to refuse treatment.[14] Notably, these provisions apply to all medical testing and treatment, even for conditions that do not have a specific testing or treatment law of their own.

For its part, a New York hospital has an affirmative obligation to afford each patient the opportunity to exercise each of those rights, including the right to refuse treatment.[15] This is not a value that is exclusive to New York—the recommendations of the Centers for Disease Control,[16] the World Health Organization[17] and the American Nurses Association's Code of Ethics[18] also all stress the importance of informed consent to treatment.

The uninformed, nonconsensual HIV testing outlined in this proposal is inconsistent with those essential values and the letter of the law. Providers who engage in medical testing without a patient's consent have, by definition, failed to fulfill their legal obligation to fully counsel the patient with respect to the risks and benefits of the procedure and secure informed consent. Most troublingly, a patient who has been tested without their knowledge and verbal consent has also been deprived of any opportunity to assert their own rights to be informed and to consent or not consent to the treatment as that patient was not made aware of the testing when it occurred.

Indirect Forms of "Notice" Are Not Sufficient for HIV Testing and Violate the Americans With Disabilities Act

While advocates might argue that even without a requirement of direct notice, patients may still be provided with notice in other forms, those indirect forms of notice will not suffice for

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[12] Pub. Health § 2803(1)(g).

[13] 10 N.Y. Comp. Codes. R & Regs. Tit. 10 § 405.7 (c)(9).

[14] *Id*. at § 405.7(c)(11).

[15] *Id*. at § 405.7(b)(1) and 405.7(b)(10).

[16] "CDC Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health Care Settings," *available at* https://www.cdc.gov/mmwr/preview/mmwrhtml/rr5514a1.htm ("Patients should be informed orally or in writing that HIV testing will be performed unless they decline (opt-out screening). Oral or written information should include an explanation of HIV infection and the meanings of positive and negative test results, and the patient should be offered an opportunity to ask questions and to decline testing.").

[17] "Consolidated Guidelines on HIV Testing Services," *available at* https://apps.who.int/iris/bitstream/handle/10665/179870/9789241508926_eng.pdf;jsessionid=B9A60A216A0A64036011E9A7D29EE81C?sequence=1 ("HIV testing for diagnosis must always be voluntary, consent must be informed by pre-test information, and testing must be linked to prevention, treatment, care and support services to maximize both individual and public health benefits.").

[18] *Code of Ethics for Nurses*, *available at* https://www.nursingworld.org/coe-view-only *at* Section 2.1 ("The nurse's primary commitment is to the recipients of nursing and health care services…. When the patient's wishes are in conflict with those of others, nurses help to resolve that conflict. Where conflict persists, the nurse's commitment remains to the identified patient.").

many patients. Notices on the walls of busy urban clinics, emergency rooms and subways do not constitute sufficient notice to a person presenting for care that they must assert an objection at some point in their admission and testing process to avoid being tested for HIV. This approach ignores the fact that many of those relying on these services will not have functional vision, cannot read, or have mental or cognitive impairments, and often present in the kind of physical distress from acute pain or illness that precludes simultaneously understanding that at some unidentified point they must speak up and object or be tested for HIV. Because the proposal subjects people with disabilities to a process that effectively deprives them of their right to refuse unwanted testing and treatment it is a clear violation of the Americans With Disabilities Act as well as other state and federal laws that protect individuals with mental health disabilities and substance use.

The proposal also ignores the reality that for some with undocumented immigration status, testing for HIV while being treated for the flu or other acute health care needs may place their ability to stay in or return to this country in peril.[19] [20] It ignores the all too frequent scenario of mentally ill or minority individuals being brought into an ER for injuries sustained after "resisting arrest;" with this proposal, arresting officers will now have HIV test results which can turn a mishandled arrest of a person on the basis of a disability into a felony charge for the arrested individual. In short, there are multiple reasons why the proposed approach to "notice" will be meaningless for most individuals, and why it may be in the best interest of many individuals to choose to test for HIV at another time and in another setting.

Changing the Testing Law May Not Even Result in More Testing, Nor Will it Increase Engagement in Care Needed to Prevent Further HIV Transmission

It is far from clear that the public health benefits of nonconsensual HIV testing outweigh the considerable risks. While advocates may stress the potential benefits of increasing the number of people engaged in treatment, they offer little evidence that this proposal will accomplish that. Should we expect that providers who continue to violate state law by failing to offer HIV testing will now engage in conversations with patients testing positive about the meaning of those results, the benefits of ART and regular physician visits, and how to connect with appropriate providers and treatment options?

There is scant evidence that eliminating notice and verbal consent for HIV testing will actually result in higher rates of testing or engagement in treatment, and the evidence most commonly marshaled in support of such proposals is often confounded by other barriers to testing and treatment, such as the reluctance of many medical providers to engage in open conversations with patients about HIV and the effects of HIV stigma on both providers and patients.[21] Nor does this proposal take into account the myriad ways that testing without notice, consent, or transparency could erode trust between patients and medical providers, especially given the HIV stigma and discrimination that many patients will have experienced

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[19] *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.").

20 *See* Gruberg, Sharita, *How Policy Entanglement with Immigration Enforcement Puts LGBTQ Lives at Risk*, Center for American Progress (April 12, 2017), *available at* https://www.americanprogress.org/issues/lgbt/reports/2017/04/12/430325/police-entanglement-immigration-enforcement-puts-lgbtq-lives-risk/.

[21] For example, proponents often point to successes in increasing the rate of Hepatitis C testing since New York reformed that law in 2014, but that testing regimes differs in key ways from the proposed reform to the HIV testing law; most notably, New York does *not* permit persons to be tested for Hepatitis C without notice or consent, so it is unclear how any improved rates testing for Hepatitis C over the past five years militate for dispensing with notice and consent for HIV testing. Rather, improved rates of Hepatitis C testing may stem from the new requirement that tests be automatically offered to certain individuals, a reform that brought that statute in line with current laws around HIV testing. *Compare* Pub. Health §§ 2171 *and* 2781.

both in the medical and legal establishment.[22]

A balanced analysis of this proposal would fully consider the possibility that—far from increasing access to and engagement with medical treatment—nonconsensual testing risks further alienating exactly the communities that the proposal aims to engage from pursuing further care. Patients might think twice about seeking other medical treatment that they need for fear that they might be subjected to further testing or interventions without their notice and consent.

This concern is particularly acute in communities of color, which have long suffered disparate health outcomes—including substantially increased mortality from many chronic diseases when compared to white peers—borne of diminished access to treatment and agency within treatment settings.[23] In response, far from suggesting that standard practices of notice and consent should be discarded, social scientists have proposed working even more closely and openly with members of affected communities to design more effective policies.[24] That specific recommendation has been echoed with respect to people living with HIV—as one article notes, "Legal protections for people living with HIV and AIDS, together with appropriate reporting and enforcement … have provided powerful and rapid means of mitigating the worst effects of the unequal power relations, social inequality and exclusion that lie at the heart of processes of HIV and AIDS-related stigmatization and discrimination."[25]

The Proposal Would Benefit from Further Deliberation

This new proposal to eliminate notice and verbal consent for HIV testing touches on complicated issues of agency and threatens to upset a delicate balance between communities affected by HIV and their medical providers. The proposal would benefit from a thoughtful and deliberative process that incorporates all stakeholders in the conversation and acknowledges the complex dynamics of HIV discrimination and stigmatization. While we accept that the urgency expressed by advocates of this proposal is inspired by their desire to engage more people in treatment, we do not believe that a process devoid of inclusion and transparency will achieve that goal.

Moreover, this conversation would benefit from a full consideration of not only this proposal but also of alternative approaches that preserve individual autonomy and dignity while offering a more robust likelihood of long-term success. If ensuring that everyone who has not tested for HIV has a real opportunity to know their status and get treatment is a priority, those who have not yet been tested can be routinely offered a home testing kit, so that they are encouraged to find out their status in a setting that feels safe and appropriate for them. Rather than relax patient protections, we could instead enlist the hundreds of PLHIV who are both trained peer counselors and are ready and able to speak with people in medical settings in the neighborhoods where they live to explain HIV, the benefits of testing, and options for when and where to be tested, including during their current visit. We could adopt a process for identifying providers who continue to violate the law along with meaningful incentives other than elimination of patient verbal consent and meaningful penalties for the

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[22] *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*, Journal 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.

[23] *In Focus: Reducing Racial Disparities in Health Care by Confronting Racism*, The Commonwealth Fund, September 27, 2018, *available at* https://www.commonwealthfund.org/publications/newsletter-article/2018/sep/focus-reducing-racial-disparities-health-care-confronting.

[24] *Id*.

[25] Aggleton, Peter and Richard Parker, *HIV and AIDS-related Stigma and Discrimination: A Conceptual Framework and Implications for Action*, Social Science & Medicine 57 (2003), 13–24.

intractable violators.

We respectfully ask that you reconsider your support and sponsorship for this proposal. We also ask that you postpone any contemplated introduction of a bill along these lines, to allow a broader, more inclusive examination of the real and potential harms that elimination of notice and consent for HIV testing poses and the availability of other, more promising solutions.

We would welcome the opportunity to meet with you to discuss our position further.

Respectfully,

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