

Why HIV Privacy Laws Matter

More than two decades have elapsed since the first HIV cases were identified in the United States, but the unfortunate reality is that there is still stigma associated with HIV. Too often, disclosure that a person has HIV wreaks havoc on that person's life. The Centers for Disease Control and Prevention caution health care workers to avoid revealing a patient's positive HIV test results even to the patient's family and friends without the patient's consent because "of the risk of stigma and discrimination."¹ The stigma often associated with HIV-positive status harms both the individual and the public health. Stigma has been linked to failure to get tested for HIV, delays in seeking medical care by those who have HIV, poor access to medical care, nonadherence to antiretroviral treatment, and faster disease progression.² Keeping HIV records confidential therefore remains as important as ever.

On September 9, 2010, Lambda Legal, the American Civil Liberties Union of Northern California (ACLU-NC), and HIV & AIDS Legal Services Alliance (HALSA) sent a [letter to David Maxwell-Jolly](#), Director of the California Department of Health Care Services, demanding a full explanation for the unauthorized and illegal disclosures of confidential identifying information of approximately 5,000 HIV-positive Medi-Cal recipients. The information was released over a two-and-a-half-year period, beginning in 2007, to a third party service provider. In addition, Lambda Legal, the ACLU-NC, and HALSA seek immediate assurances from the state agency that no additional unauthorized, illegal disclosures will occur.

Lambda Legal and ACLU-NC became aware of the breach during discussions about AB 2590, a bill which aimed to dilute the strong confidentiality protections under California law for those with HIV/AIDS and to legalize the unauthorized release of such information to an HIV/AIDS service provider. Although current law forbids unauthorized disclosures about a person's HIV status, the state agency released confidential identifying information about HIV-positive Cal recipients without authorization or proper limitations on how that information was to be used by a private organization, the Los Angeles-based AIDS Healthcare Foundation.

Laws prohibiting the unauthorized disclosure of HIV status exist for good reason. Based on the hundreds of calls Lambda Legal receives each year from affected people nationwide, we know first-hand of the discrimination and harm that often follow the disclosure of a person's HIV-positive status. We received 454 complaints of HIV discrimination in 2009 alone, and 403 in 2008. Breaches of confidentiality consistently rank among the three most common forms of HIV-related problems that prompt requests for our help. These figures echo social science research findings, such as the 2006 survey of health care providers in Los Angeles County by the Williams Institute at UCLA, which found that 55 percent of obstetricians, 46 percent of skilled nursing facilities, and 26 percent of plastic and cosmetic surgeons would refuse to treat patients living with HIV.³

The cases we litigate similarly confirm that HIV-positive people still frequently encounter bias in a broad, troubling range of settings when their serostatus is known. Robert Franke was turned away from an assisted living facility;⁴ Cecil Little was turned away from a *series* of nursing homes.⁵ Melody Rose was denied gall bladder surgery.⁶ Bob Hickman was fired from his job as a restaurant manager.⁷ Matthew Cusick had his circus performer job offer rescinded.⁸ In all of these cases, Lambda Legal was able to achieve a measure of redress for our clients, but no one can unring the discrimination bell and prevent the hurt and loss.

It is especially appalling when government breaches the confidentiality of personal medical information, thereby creating risk of discrimination. Stanmore Cooper had to seek redress in court after his HIV status was wrongfully shared among the Federal Aviation Administration, the Social Security Administration, and the U.S. Department of Transportation, all without his consent.⁹ We also have litigated against the Department of Veterans Affairs for the unauthorized disclosure of a patient's HIV status to a third party.¹⁰

In this instance, the large-scale, unlawful release of confidential patient information by California's Department of Health Care Services not only violates patient privacy and autonomy, but also undermines public health. People are more likely to get tested for HIV when they know that their test results will remain private. Patients are more likely to comply with a medical care regimen when their privacy rights and personal autonomy are respected. That is particularly true with respect to chronic illnesses such as HIV, where health outcomes rely upon patient adherence to a long-term medical care regimen.

Yet it is difficult to imagine a more off-putting start to medical care than to learn that one's HIV status has been revealed to a total stranger—and by the very entity that is supposed to protect public health. The fact that the stranger here is a service provider does not make the unauthorized disclosure legal, nor does it make the privacy invasion any less shocking. None of us would want private clinics or pharmaceutical companies personally soliciting us uninvited in the privacy of our homes, urging us to purchase treatment or drugs after targeting us using information about our intimate health conditions that the law requires be kept confidential.

Lambda Legal's letter demands that the state agency comply with California law and stop releasing confidential health information to third party service providers. It also demands that the state agency provide a full accounting of exactly what information was released. Lambda Legal, the ACLU, and HALSA have also submitted a request under the California Public Records Act requesting documents regarding the release, with the confidential information removed.

To see the letter, go to www.lambdalegal.org/ld-medical-hiv-patients, and click here to [see the press release](#).

¹ Centers for Disease Control and Prevention, "Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-Care Settings," 55 *Morbidity and Mortality Wkly. Rep. Recommendations and Repts. No. RR-15* (2006), at 10, *available at* <http://www.cdc.gov/mmwr/PDF/rr/rr5514.pdf>.

² *See, e.g.*, Anish P. Mahajan *et al.*, "Stigma in the HIV/AIDS Epidemic: A Review of the Literature and Recommendations for the Way Forward," 22 (*Suppl 2*) *AIDS S67-S69* (2008); Margaret A. Chesney & Ashley W. Smith, "Critical Delays In HIV Testing and Care: The Potential Role of Stigma," 42(7) *Am. Behavioral Scientist* 1158, 1159-60 (1999).

³ Brad Sears & Deborah Ho, "HIV Discrimination in Health Care Services in Los Angeles County: The Results of Three Testing Studies," Williams Institute (2006), *available at* <http://www.law.ucla.edu/williamsinstitute/pdf/Discrimination%20in%20Health%20Care%20LA%20County.pdf>.

⁴ *See* Lambda Legal, *Franke v. Parkstone Living Ctr.*, No. 09-341 (E.D. Ar.), <http://www.lambdalegal.org/in-court/cases/franke-v-parkstone-living.html>.

⁵ *See* Lambda Legal, *In re Little* (H.H.S.), <http://www.lambdalegal.org/in-court/cases/in-re-cecil-little.html>.

⁶ *See* Lambda Legal, *Rose v. Cahee*, No. 09-142, 2010 U.S. Dist. LEXIS 74107 (E.D. Wis. July 22, 2010), <http://www.lambdalegal.org/in-court/cases/rose-v-cahee-et-al.html>.

⁷ *See* Lambda Legal, *Hickman v. Donna Curry Investments*, No. 06-127 (D. Nev.), <http://www.lambdalegal.org/in-court/cases/hickman-v-donna-curry-investments.html>.

⁸ *See* Lambda Legal, *Cusick v. Cirque du Soleil* (E.E.O.C.), <http://www.lambdalegal.org/in-court/cases/matter-of-matthew-cusick-and-cirque-du-soleil.html>.

⁹ *See* *Cooper v. FAA*, 596 F.3d 538 (9th Cir. 2010).

¹⁰ *See* Lambda Legal, *Doe v. Dep't of Veterans Affairs*, 474 F. Supp. 2d 1100 (D. Minn. 2007), *aff'd*, 519 F.3d 456 (8th Cir. 2008), <http://www.lambdalegal.org/in-court/cases/doe-v-department-of-veterans.html>.