



September 9, 2010

Via Facsimile and Email

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Director
California Department of Health Care Services
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RE: Release of Confidential Information of HIV-Positive Medi-Cal Patients

Dear Dr. Maxwell-Jolly,

It has recently come to the attention of the ACLU of Northern California (ACLU), Lambda Legal, and the HIV and AIDS Legal Services Alliance (HALSA) that the Department of Health Care Services (DHCS or the Department) released to a contractor the HIV status and confidential identifying information of approximately 5,000 HIV-positive Medi-Cal recipients. We now seek a full explanation of this disclosure, which appears to be a clear violation of both California statutory and constitutional law and a gross affront to the privacy of HIV-positive Medi-Cal recipients. We also seek assurances from the Department regarding the steps it will take in the future to protect the privacy interests of HIV-positive Medi-Cal recipients.

Factual Background

In February of this year, California State Assemblymember Bonnie Lowenthal introduced a bill, AB 2590, which would have amended California's Health and Safety Code to allow "the results of a blood test to detect HIV" to be disclosed to "contractors of the state that are authorized to provide medical care and treatment to test subjects" without written authorization by the test subject. For the ACLU, Lambda Legal, and HALSA, as well as other organizations and advocates dedicated to combating discrimination against HIV-positive Californians, the bill

raised a number of privacy concerns that were in no way addressed in the text of the bill. The bill did not explain, for example, the purpose(s) behind allowing the contractors to receive such confidential information from the State despite the privacy interests of the affected HIV-positive individuals, nor did the bill provide any limitations on how the contractors could use the information.

A fact sheet on AB 2590, prepared by Rose & Kindel, the lobbying firm for the AIDS Healthcare Foundation (AHF), claimed that the bill was needed because AHF, an organization that had contracted with the State “to provide disease management to Californians with HIV/AIDS,” was having difficulty finding HIV-positive persons to enroll in its program.¹ As stated in the fact sheet, current law “limits information sharing about a person with HIV/AIDS” and “has been interpreted to limit the provision of data to a provider that is authorized and funded by the state to provide care and treatment to people with HIV/AIDS.”² In other words, according to the fact sheet, the bill intentionally attempted to dilute the strong privacy protections currently provided to people with HIV/AIDS under California law, in an effort to allow the State to release confidential identifying information about HIV-positive Californians that contractors such as AHF then could use to try to track down these individuals. The fact sheet also did not identify the methods by which AHF proposed to pursue and solicit HIV-positive Californians under the proposed legislation, nor did it mention whether AHF would take any steps to protect these patients’ privacy as it sought to find and enroll them in its program.

During discussions about AB 2590 between HIV/AIDS advocacy organizations and the Department, the Department explained that it had entered into a contract with AHF in 2007, under which AHF agreed to conduct a “Disease Management Pilot Program” (DMPP) for HIV-positive Medi-Cal recipients. This contract requires AHF to “provide or arrange for all DM [disease management] covered services . . . to HIV/AIDS DMPP Members,” which include “outreach and assessment; enrollment/disenrollment; disease management; case management; health advice line; assistance in finding a medical home; and member education.”³

As part of the “enrollment/disenrollment” function under the contract with DHCS, AHF further agreed to “make a good faith effort to contact all potential Members with information regarding the HIV/AIDS DMPP benefits, services and enrollment/disenrollment procedures.” According to the contract, “potential Members” *are derived from lists supplied by DHCS on a monthly basis*. Persons are eligible for the DMPP if they are eligible for Medi-Cal, are at least 22 years old, and have a “primary or secondary diagnosis of HIV/AIDS,” unless they were excluded on the basis of other enumerated criteria.⁴ Inclusion on these lists apparently reflected, at least, that the persons were potentially eligible to participate in the DMPP.

¹ Fact Sheet re AB 2590 distributed by Rose & Kindel.

² *Id.*

³ Agreement between AIDS Healthcare Foundation & DHCS, Agreement No. 07-65584, Ex. A, Attachment I, Section G (dated Oct. 12, 2007).

⁴ *Id.*

From the plain language of the Department's contract with AHF, it is clear that even without the passage of AB 2590,⁵ the Department is already disclosing confidential identifying information about HIV-positive Medi-Cal recipients to AHF. In fact, the Department has openly admitted doing so: in email correspondence with the San Francisco AIDS Foundation, a Department representative stated that DHCS had released the confidential identifying information of approximately 5,000 HIV-positive Medi-Cal recipients to AHF, including names, addresses, and phone numbers.

In a subsequent email and in response to a direct question about whether DHCS was prohibited from disclosing confidential identifying information about HIV-positive persons under California's Health and Safety Code, the DHCS representative explained that "there isn't a specific exemption anywhere in the statute" that would allow for the disclosure, that the "issue is very complex with numerous statutes addressing the issue," and that DHCS legal staff was involved in the contracting of AHF and attempted to make sure that "everything complied with statutory requirements."

Legal Analysis

The Department's disclosure of confidential identifying information about HIV-positive Medi-Cal recipients appears to be a clear violation of California's statutory law and the California Constitution.

First, California Health & Safety Code § 120980 imposes civil and criminal penalties⁶ on any person who negligently, willfully, or maliciously discloses "the results of an HIV test" to any third party, if the disclosure allows identification of the test subject without the subject's authorization. Here, the disclosure of the names and other confidential identifying information of HIV-positive Medi-Cal recipients by DHCS to AHF plainly constitutes the disclosure of the results of the recipients' HIV tests – as DHCS admits⁷ – and it is our understanding that the information was disclosed by DHCS to AHF without the authorization of each individual Medi-Cal recipient.

Nor is there any exemption in the statute that would allow DHCS to disclose confidential identifying information about HIV-positive Medi-Cal recipients to a contractor such as AHF without the authorization of the individual recipients, as, again, DHCS itself recognizes. Indeed, the existence of other, inapplicable exemptions – such as for reports to state public health officials and the Centers for Disease Control and Prevention – indicates that the Legislature

⁵ Since May 28, 2010, AB 2590 has been held under submission in the House Appropriations Committee.

⁶ The financial liability for unauthorized disclosures can be quite large, including penalties for each disclosure of protected information and damages for harm caused by each disclosure. Health & Safety Code § 120980.

⁷ A DHCS representative conceded in an email that: "Health and Safety Code section 120980 imposes civil penalties for negligently or willfully disclosing the results of an HIV test except pursuant to a written authorization. Giving someone a list of people whose HIV status is positive is tantamount to disclosing the results of the test."

considered the range of government officials and public health professionals who might seek access to information about HIV-positive individuals and intentionally excluded government contractors from those authorized to access it without the patient's consent.

Second, California courts have consistently recognized that there is a legally protected privacy interest under the California Constitution in medical information generally and information about HIV status in particular. *See, e.g., Hill v. National Collegiate Athletic Ass'n*, 7 Cal. 4th 1, 41 (1994) (re medical information); *Urbaniak v. Newton*, 226 Cal. App. 3d 1128, 1140 (1991) (re HIV information, stating "[t]here can be no doubt that disclosure of HIV positive status may under appropriate circumstances be entitled to protection under article I, section 1[of the California Constitution]."). Where, as here, the Medi-Cal recipients did not consent to the disclosure of their confidential identifying information and the disclosure easily could have resulted in other people learning their private HIV test result information, there is little question that the disclosure raises serious constitutional concerns.

Finally, the fact that DHCS was involved in negotiations surrounding AB 2590 – a bill that aimed explicitly to give DHCS the right to disclose confidential identifying information about HIV-positive Medi-Cal recipients to contractors such as AHF⁸ – demonstrates that the Department knows that its disclosure of such information to AHF is not permitted under existing California law.

The Importance of Privacy Protections for HIV-Positive Californians

As the California Legislature has repeatedly recognized, HIV/AIDS has been and continues to be a highly stigmatized disease, and people with HIV/AIDS constitute a vulnerable population that is often subject to discrimination. In its fact sheet in support of AB 2590, AHF describes California's current law as having been "adopted during the early days of the AIDS epidemic," implying that such laws are no longer needed. This is simply not the case: even though there has been significant public education about HIV transmission and treatment, and an HIV diagnosis need not be the fast death sentence it was for many in California at one time, new infection rates persist at distressing levels. More to the point, the unauthorized disclosure of one's HIV status can still cause great harm.

The unfortunate fact that there is still stigma associated with having HIV was recently acknowledged at the highest level of our government. As the National HIV/AIDS Strategy for the United States – issued by the White House Office of National AIDS Policy in July 2010 – states, "[t]he stigma associated with HIV remains extremely high and fear of discrimination causes some Americans to avoid learning their HIV status, disclosing their status, or accessing medical care."⁹ Research confirms that HIV is viewed more negatively than many other stigmatized conditions. For example, a 2009 national survey conducted by the Kaiser Family Foundation revealed not only that many people still lack basic knowledge about how HIV is

⁸ As drafted, AB 2590 also raised serious constitutional privacy concerns.

⁹ White House Office of National AIDS Policy, "National HIV/AIDS Strategy for the United States," at ix (July 2010), available at <http://www.whitehouse.gov/sites/default/files/uploads/NHAS.pdf>.

transmitted, but also that such ignorance is continuing to fuel stigma against and the ostracism of people living with HIV. The data showed 51% reporting that they would be uncomfortable having their food prepared by someone with HIV, 42% who would be uncomfortable with a roommate with HIV, and 35% who would be uncomfortable if their child had an HIV-positive teacher.¹⁰

The disclosure that a person has HIV frequently wreaks havoc on that person's life – with stigma and/or discrimination affecting numerous aspects of the person's life.¹¹ The Centers for Disease Control and Prevention caution health care workers to avoid revealing positive HIV test results even to family and friends of patients “[b]ecause of the risk of stigma and discrimination.”¹² The stigma associated with HIV infection harms both the individual and the public health. Stigma directed at those known to be HIV-positive has been linked to failure by others to get tested for HIV, delays in seeking medical care by those who know they have HIV, poor access to care due to health care provider bias, nonadherence to antiretroviral treatment, and faster disease progression – all of which have serious public health consequences, in addition to harming the directly affected individuals. In addition, there continues to be HIV-based discrimination in employment, insurance, housing, and public accommodations.

While the goal of providing appropriate health care to HIV-positive individuals is urgent, important, and a shared priority of the undersigned organizations, we know it need not and must not come at the expense of those patients' privacy rights, autonomy, and security. What AB 2590 attempted to allow – and DHCS has already effected – is the disclosure of confidential identifying information of thousands of HIV-positive Medi-Cal recipients to AHF, without the authorization of those individuals. This not only violates current California law, as discussed above, but it also subverts public policy, showing an egregious indifference to the significant privacy concerns of HIV-positive people and risking harm to the health and wellbeing of those California residents made especially vulnerable by their low-income status. And the purpose

¹⁰ Kaiser Family Foundation, “2009 Survey of Americans on HIV/AIDS: Summary of Findings on the Domestic Epidemic,” at 4, 21 (Chart 27) (2009), *available at* <http://www.kff.org/kaiserpolls/upload/7889.pdf>. In fact, the survey showed that “levels of knowledge about HIV transmission have not improved since 1987.” *Id.* at 4-5.

¹¹ *See, e.g., Kinzie v. Dallas County Hosp. Dist.*, 239 F. Supp. 2d 618, 639 (N.D. Tex. 2003) (noting that people living with HIV “must deal with the social stigma of being HIV-positive” and “will likely be treated as [] outcast[s] by many . . .”), *aff'd*, 106 F. App'x 192 (5th Cir. 2003); B. Sears & D. 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> (reporting that studies conducted from 2003 to 2005 found that 55 percent of obstetricians, 46 percent of skilled nursing facilities, and 26 percent of plastic and cosmetic surgeons in Los Angeles County refused to treat patients living with HIV).

¹² 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 Reps.* No. RR-15 (2006), at 10, *available at* <http://www.cdc.gov/mmwr/PDF/rr/rr5514.pdf>.

behind this disclosure – helping AHF to market its services directly to this population – makes the disclosure even more difficult to understand. Efforts by a private organization to use government-gathered, confidential information to track down individual Medi-Cal recipients to market services to them likely will cause many to feel exposed and even harassed upon being contacted and pursued by strangers who, out of the blue, have acquired the individuals' personal medical information, while also putting those individuals at increased risk of further unauthorized disclosures of their HIV status to others.

For example, a Medi-Cal recipient's HIV status may be revealed to a family or household member, neighbor, or landlord simply by delivery of a letter from AHF. Similarly, a recipient's HIV status may be exposed by a phone call or an unscheduled, in-person visit from an AHF representative. Yet more troubling, it is our understanding that through AB 2590, AHF sought to obtain from DHCS even more information than the names and contact information of HIV-positive Medi-Cal recipients, including information about treating doctors. This raises the alarming possibility that a contracted services provider such as AHF could pursue HIV-positive Medi-Cal recipients who had already made the decision to receive medical services from their current health professional, or from an organization that treats a range of patients and patient needs, rather than one, like AHF, dedicated HIV/AIDS care.

The establishment of a system in which any Medi-Cal recipient who is tested for HIV is at risk of the public disclosure of his or her HIV status, of exposure to the stigma associated with HIV, and of uninvited direct marketing to accept services from a particular private provider is likely to have the pernicious effects described above: increased failure of individuals to get tested for HIV, delays in HIV-positive individuals seeking medical care, nonadherence by some to antiretroviral treatment, and faster disease progression of HIV-positive individuals. This surely cannot be the goal of DHCS, which claims as its mission to "preserve and improve the health status of all Californians."

Conclusion

The ACLU, Lambda Legal, and HALSA are shocked and dismayed by the Department's blatant disregard of both California law and the privacy of HIV-positive Californians in its release of the confidential identifying information of approximately 5,000 HIV-positive Medi-Cal recipients to AHF. We strongly urge DHCS to take the following steps:

- Provide immediate assurance that the Department will guard the privacy of HIV-positive Medi-Cal recipients, as required by current law;
- Provide immediate assurance that the Department will not re-disclose information or disclose additional information about any of the approximately 5,000 HIV-positive Medi-Cal recipients whose confidential identifying information was previously disclosed to AHF;
- Provide immediate assurance that the Department will not disclose additional identifying information about HIV-positive Medi-Cal recipients to AHF or any other

- contractor providing HIV/AIDS-related treatment or disease management services without explicit written authorization from the Medi-Cal recipients themselves;
- Provide a full explanation of the Department's disclosure of the identifying information of the approximately 5,000 HIV-positive Medi-Cal recipients to AHF (as described by DHCS's representative), including:
 - Whether the Department obtained authorization from the HIV-positive Medi-Cal recipients whose confidential identifying information it disclosed to AHF;
 - If the Department did not obtain authorization from the HIV-positive Medi-Cal recipients whose confidential identifying information it disclosed to AHF, why not; and
 - If the Department did not obtain authorization from the HIV-positive Medi-Cal recipients whose identifying confidential information it disclosed to AHF, under what authority it made the disclosures; and
 - Fully respond in a timely fashion to the Public Records Act request submitted simultaneously with this letter.

Please let us know no later than **September 23, 2010**, what steps the Department intends to take with respect to this matter. Failure to promptly take the appropriate remedial measures listed above could increase the risk of litigation over these unauthorized disclosures, which have affected the legal rights of thousands of HIV-positive Californians.

Sincerely,

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