HIV/AIDS and the LGBT Legal Community

Remarks at the 2013 Lavender Law Conference urge a recommitment to the fight against the virus.

September 5, 2013 By Scott Schoettes

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Good morning, my name is Scott Schoettes, and I am the HIV Project Director at Lambda Legal.

I first want to thank the leadership of the National LGBT Bar Association for asking me to speak on this panel this morning. I am truly humbled to speaking as part of this plenary in the company of these amazing co-panelists. I promise you I am not being falsely modest when I say I am not exactly sure how I was selected to be on this illustrious panel. But since I have been given this opportunity, I hope to make the most of it, so I am going to jump right in.

I am going to start by quoting from a joint statement on HIV/AIDS that was issued by the leaders of 35 LGBT organizations, and subsequently endorsed by over 100 others, just this past spring.

Quote: "Over the last 30 years, the lesbian, gay, bisexual and transgender community has seen great strides in the movement for full equality. Much of this success is the result of a concerted movement, which was galvanized in response to the AIDS epidemic in the 1980s.

"In the decades since, our movement has seen incredible victories. Today, twenty-one states and Washington, DC, have implemented nondiscrimination laws in employment to protect LGBT employees. Eighteen states allow gay couples to adopt children.

"Sixteen states have passed legislation protecting LGBT students from discrimination, with another fifteen states specifically protecting LGBT students from bullying. Gays and lesbians can now serve openly in the military and more than half of all Americans support marriage equality, including the first-ever sitting president.

"Unfortunately, our community hasn't maintained the same momentum in our fight against HIV. Gay and bisexual men recently accounted for 63% of all new HIV infections and perhaps most concerning is the 22% increase among those between 13 and 24 years old. Each day, more than eighty gay and bisexual men become infected with HIV in the United States.

"These trends are even more pronounced among gay and bisexual men of color, with young black gay and bisexual men having a higher rate of HIV infection than any other population in this country."

And I am going to break from quoting the statement for a moment, to caveat that by saying "any other population for which we collect adequate data," because as the statement goes on to say:

"While we don't have enough data on transgender populations, studies show that 28% of transgender women are HIV positive in the United States, with rates over 50% for African American transgender women.

"One in five gay and bisexual men are living with HIV in the United States. Despite these alarming statistics, which have galvanized our community in the past, the HIV epidemic has seemed to fall by the wayside. Many in our community have simply stopped talking about the issue. This must change."

This ... must ... change. I couldn't agree more.

Some parts of the LGBT community, it seems, have been engaged in a bit of soul-searching on the topic of our engagement on HIV/AIDS issues, and though it is not always the most comfortable thing to do, I am going to invite us, as the LGBT legal community, to do a bit of the same soul-searching here this morning.

I hope those who so graciously invited me to speak here today will forgive me if take this opportunity to point out that Lavender Law has not been immune to the phenomenon described by this statement; not able, perhaps, like a large swath of the more privileged members of the LGBT community, to resist the quite natural desire to "disown" HIV/AIDS as a health crisis centered in our own community; and that has, like many of the LGBT organizations who signed on to that statement—not to mention the ones that did not—been sometimes just a little too willing, it seems, to let others take the lead in the battles that remain to be fought on behalf of those living with and affected by HIV.

So while I am here today to talk about the past 25 years of Lavender Law in relation to HIV/AIDS—and to celebrate the many successes that we have had in the fight against this disease and, in particular, that this legal community has achieved in reducing the stigma, inequality and social injustice that fuels this epidemic—I am also here to issue a challenge, a challenge to the leadership and the membership of this organization, as well as the legal community more broadly, to re-engage on this issue and to re-focus some of its tremendous energy and formidable capabilities on doing what we can to help end the epidemic that continues within our community, right here in these United States.

While we all know HIV/AIDS is not exclusively a "gay disease," as it was considered at the very beginning of the epidemic, it is undoubtedly a disease that has had—and, though to a lesser-degree than during its peak, continues to have—a devastating impact within our community.

So, with that said, to put this all in context, let me take us back to where things stood in 1988, the year of the first Lavender Law conference. It was only 7 years earlier that the first deaths from what was originally dubbed a "gay cancer" started to occur in New York City, San Francisco, and Los Angeles. I won't try to describe what it was like to be a gay or bisexual man, or transgender person, in those communities at that time, with the dawning realization that the community's members were being systematically targeted and subjected to a painful illness and slow, lingering death by this shadowy killer. I am not able to speak from personal experience about that subject, and even if I was, this is probably

not the proper venue or medium through which to convey what it must have been like.

What I will do here today is describe the manner in which the LGBT community came together to address the growing problem—and, in particular, I'll talk about the way in which lawyers were, are, and continue to need to be, a part of that response.

Because HIV/AIDS first took hold within specific populations that were already marginalized in one way or another, it fairly quickly became apparent that this epidemic was going to require not just a scientific and medical response, but also a legal, political and human rights-based one.

Of the groups most heavily impacted at the beginning of the epidemic, and for those of you weren't alive—I know we have a relatively young audience here at Lavender Law—so for those of you who weren't alive or aren't as familiar with the history, those four groups were somewhat derisively described by some as the "4H Club"—meaning homosexuals, hemophiliacs, Haitians, and heroin users—of those groups, the only group that was really organizing politically prior to the epidemic was this one, the "homosexuals." So it was pretty natural for the lawyers of the burgeoning gay civil rights movement to step into the role of lawyers for those affected by HIV/AIDS.

But I also don't want to give the misimpression that there was some powerful gay civil rights—and I am using the term "gay" here intentionally, because we were not yet the together as the trans-inclusive community that Phyllis [Frye] described earlier—we were not some powerful train hurtling along that HIV/AIDS advocates simply latched on to in order to secure their rights and catapult themselves into some degree of political power. In fact, just the opposite was true in many respects. To be sure, there was a nascent gay civil rights movement underway when the AIDS crisis hit, but it was nothing like the veritable juggernaut it is today.

In 1981, at the dawn of AIDS, we were barely a decade away from Stonewall, so the LGBT and HIV/AIDS advocacy movements really came of age together and in a somewhat symbiotic relationship, with the HIV/AIDS side accelerating the process—particularly on the political front—because of the impact and urgency of the crisis facing the GBT portion of our community. As the statement I read says, it was a crisis that galvanized us as a community.

So, from the very outset, it was the gay legal groups that stepped up to address, at least the most pressing, legal needs of people with HIV. It was, in fact, my organization, Lambda Legal, that represented Dr. Joseph Sonnabend in what is generally regarded as the first HIV discrimination case in 1983.

Dr. Sonnabend was one of the medical pioneers, treating people—primarily gay men—who were coming down with and succumbing to what was by this point sometimes being called GRID, which stood for Gay-Related Immunodeficiency Disorder, and he was doing so from his offices on the ground floor of a rather nice co-op building on the West Side of New York.

Well, the tenants association of the co-op decided that they did not like or want visibly sick—and sometimes quite apparently dying—people going in and out of their building to receive medical services, so they attempted to evict the good doctor.

Lambda Legal filed suit and helped obtained a preliminary injunction preventing that eviction, and the parties later reached a resolution that allowed Dr. Sonnabend to continue his practice from that location.

It was an early and important victory in the legal battles on behalf of people living with HIV, to be sure, but one that, by no means, became the "norm." There were three major legal initiatives launched shortly after that—one, to prevent the closure of the bath houses, because advocates recognized that simply shutting down the bath houses would not stop people from having sex, but it would eliminate a major avenue through which to communicate with and educate the community most affected; two, an effort to prevent the licensing of the HIV test until some protections could be established to prevent discrimination based on test results; and three, suing the State Department to stop it from using HIV as a disqualifier for employment as a Foreign Service Officer—all of those efforts were completely unsuccessful.

As Abby Rubenfeld, the first Legal Director for Lambda Legal, has explained—and I think Abby might be in the audience today; I know I saw her at the reception last night—as Abby has said to this gathering before, they had the right ideas and all the correct legal theories—most of which were later vindicated—they just weren't winning any cases based on those theories.

There were very few groups focused on these tough legal battles at the time—Lambda Legal was one, and to some extent the ACLU and eventually GLAD, as well as the pre-cursor to NCLR—and please forgive me if I am leaving someone out, but it was not very many. But it was the LGBT groups that stepped in to do this work. And, I think it is hard to imagine just how difficult it must have been to litigate these cases, when we still new so relatively little about HIV, when fear of contracting HIV was running rampant, even in the medical community, and when the group of people whose rights they were seeking to protect was already marginalized in so many other ways.

The lawyers, of course, were not alone in this fight. There were groups like GMHC, the Gay Men's Health Crisis, providing care to those who had fallen ill, and eventually there was ACT UP—the AIDS Coalition to Unleash Power, which again for those of you who may not have been alive at the time, was a group of community activists who came together—at first in New York, but eventually across the country—to demand a more robust governmental response to the epidemic.

I don't really have time to do the story of ACT UP justice here this morning, but if people want a more in-depth understanding of what ACT UP was—and wasn't—able to achieve at the height of the AIDS crisis, I highly recommend that you see the documentary film How to Survive a Plague, which was nominated for an Academy Award this past year.

But back to the main story here, which is about the involvement of the legal community in this battle. In 1988, at about the same time that ACT UP was forming, the National LGBT Bar Association held its first Lavender Law Conference, right here in San Francisco. And HIV was front and center.

There was an all-day AIDS Law conference on the very first day, and then an HIV/AIDS related breakout session in every single remaining time slot of the conference, including a lunch-time "special" program on HIV treatment. The second conference, held two years later, was exactly the same—with an all-day AIDS Law conference the first day and HIV/AIDS-related programming during every breakout session thereafter.

And for the next decade, there was similarly robust HIV/AIDS programming, tracking the wide-range of legal topics affecting people living with HIV: employment discrimination, estate planning, public benefits, insurance litigation, privacy and confidentiality, consent to testing, immigration, right-to-die, health insurance reform, custody disputes, the ADA, the list goes on.

And during this same time, there were great legal strides—as well as some setbacks—for people living with HIV in many of these areas, a primary example being the Americans with Disabilities Act of 1990, followed eight years later by the landmark Supreme Court ruling on its application to people living with HIV in Bragdon v. Abbott—brought to us by our friends at GLAD.

Bragdon—involving a dentist who would not perform a dental procedure for an HIV-positive patient, because he claimed it would pose a threat to the safety and health of his staff—established once and for all that HIV was a "physical impairment" as defined in the statute, and that there were several "major life activities" that could possibly be substantially impaired by HIV, entitling those living with it to the protections of the ADA.

However, something happened on the way to claiming our civil rights under the ADA—well, actually, more than one thing happened when the holding of the Supreme Court was misinterpreted and misapplied by some lower courts—but the thing I want to focus on right now actually had a profound effect not just on the legal landscape but on the entire course of the epidemic.

You see, approximately two years before the Supreme Court decision in Bragdon, combination therapy with antiretrovirals, including protease inhibitors, was first being made available to some HIV patients. And suddenly, the people with access to those medications were walking back from the brink of death.

As we all know, these medications were not a "cure" for HIV, they did not eradicate HIV from the body—and it took a number of more years before doctors were able to get the dosages dialed in sufficiently to prevent what were intolerable side effects for many—but nonetheless the introduction of combination therapy marked a dramatic change, a turning point in the epidemic, at least for those with access to the medications and to all of the other necessary support systems to maintain strict adherence and to be routinely monitored by a healthcare provider.

On the legal side, these medications changed the landscape in many respects, because effective treatment with these medications undercut the argument that having HIV was a "disability" as defined under the Americans with Disabilities Act. And I could go on about the details of how that played out in the legal system over the years following, but I actually want to focus on the effect that this "functional cure" had on the LGBT community and the amount of attention we have been paying to HIV ever since, to HIV and the social justice issues—poverty, racial inequality, access to education and healthcare, the dehumanization of people with certain addictions or occupations—issues that had been at the heart of the HIV epidemic from the very beginning, but that have never been fully examined or adequately addressed.

At the same time, I want to contrast the intense focus on HIV/AIDS in the first dozen years of Lavender Law with the last dozen years, the years since I have been a member. I can say, quite definitively, that the issue of HIV has gradually become all but invisible at this conference since I started attending in 2000. Much in the same way that so many HIV-positive gay men of privilege have retreated back into the HIV closet during that same time.

So here comes the soul-searching that I mentioned earlier. What caused this to happen, to the amount of attention we have been paying to HIV?

Maybe it is a certain amount of HIV fatigue and there is a sense that the membership of the LGBT bar doesn’t want to talk about HIV/AIDS anymore, that it is depressing and certainly not nearly as present in

or central to the lives of young LGBT attorneys as it was once was. A belief, perhaps, that there are "sexier" and more interesting LGBT issues that will resonate with the next generation, which did not experience the HIV epidemic in the same way that my age group and those who came before me did.

Maybe it is because people think that the legal community has done its part, that the major legal issues and problems surrounding HIV have all been resolved, and therefore, it is not worth expending our time and energy on any longer.

Or maybe, maybe it is because we have decided it is no longer really our problem to deal with. In 2010, Charles King, an AIDS activist and founding member of ACT UP said: "I really truly believe that the LGBT community officially abandoned AIDS with [Andrew] Sullivan's article in the New York Times [entitled "When Plagues End"], and the reason they abandoned it was: for them it was over. It was now a black disease, not their disease. You can almost see the mark of that article and sort of the handoff, 'This is no longer our problem. We're going to move on to gay marriage and other things that pull us toward the center,' with the presumption that everybody wants to be in the center instead of at the margins."

I can't tell you which of these things or what combination of them is behind the reduced HIV/AIDS programming at Lavender Law in the past decade, because honestly, I don't know. But I will go through and debunk each one of them as a legitimate reason for continuing down this path in the future.

As to the first, that we simply don't want to talk about it anymore, I am reminded of the chilling "Silence=Death" slogan that ACT UP adopted as its message from the very beginning. One in five gay and bisexual men are living with HIV, and of the people living with HIV, 1 in 5 do not know they are infected. Not talking about it is still not an option.

I am also unconvinced by the notion that all of the major legal battles have already been won, and that it is not worth devoting our time and energy to those that remain. Many of the government's discriminatory policies barriers have only recently been changed.

It was not until 2009 that we finally took down the HIV travel and immigration ban that prevented people living with HIV from immigrating to or even visiting this country without obtaining special permission. It was not until this past Spring, thanks to the ACLU, that Alabama stopped segregating HIV-positive inmates from the rest of the population and thereby depriving them of certain rights and opportunities.

And there is much work to be done:

When a man in Atlanta is denied a job as a police officer, because of his HIV status, there is still work to be done.

When a 13-year-old boy in Pennsylvania is denied admission to a boarding school because he is HIV-positive, there is still work to be done.

When a 75-year-old man in Arkansas is kicked out of an assisted living facility because they are afraid he will transmit HIV to his caregivers, there is still work to be done.

When an immigration court tries to deport an HIV-positive transgender woman to a country where she will almost undoubtedly face persecution and perhaps serious physical violence, because that person has engaged in the "particularly serious crime" of engaging in sex work while HIV-positive in the U.S.

When our military maintains an explicit policy against admitting people with HIV—or stationing overseas those who test positive after joining the military—there is still work to be done.

And nowhere is the ongoing stigmatization and state-sanctioned oppression of people living with HIV laid more bare than in our HIV criminalization laws and the prosecutions that take place under them—just this week, through a concerted effort, we were able to beat back the criminal prosecution of an HIV-positive man making the mutual decision to have condomless sex, after disclosing his HIV status to his partner.

So I emphatically reject the notion that there is not still work to be done that is worthy of our time, energy, and attention.

Finally, the idea that somehow HIV is no longer our problem is just plain wrong and/or patently offensive, depending on which definition of "our" one is using. It is certainly our problem in the LGBT community writ large, as the statistics I quoted at the beginning of this speech all too starkly reveal.

We know that stigma and discrimination are still a primary driver of the epidemic, and that we—as lawyers—can play an important role in minimizing the stigma and discrimination that continues to surround this disease.

I am not one that buys into the false choice between marriage equality and the rest of the issues facing our community—we can do more than one thing at a time. And I fervently believe that all of the work we do to reduce stigma and discrimination against LGBT people—work that reinforces the intrinsic value of every human being and that enhances the self-esteem of young LGBT people in particular is, in some sense, HIV work.

But at the same time, we must be doing the work that directly impacts people living with HIV. Therefore, I implore this organization to put HIV back on its agenda in a meaningful way, and to join a re-committed and what is hopefully re-energized LGBT community in helping to put an end to the HIV/AIDS epidemic in this country.

Thank you.

Scott Schoettes is the HIV project director at Lambda Legal. His remarks were delivered on Friday, August 23, at the 2013 Lavendar Law conference of the National LGBT Bar Association. This article was originally published at LambdaLegal.org.

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