Trans Lives Matter

Fighting erasure and HIV.

January 8, 2018 By Kellee Terrell

You can bet your paycheck that these two things will happen if you attend the annual United States Conference on AIDS (USCA), hosted by NMAC.

First, you will sit through plenary sessions that feature AIDS celebs du jour. Second, you will watch a group of fired-up advocates, usually transgender folks, rush the stage demanding to be seen and heard. USCA 2017 in Washington, DC, was no different.

The September 8 plenary started off routinely enough, with a respected doctor in the field narrating a PowerPoint presentation of standard HIV data. But what many in the audience found jarring wasn't what was on the screen but what was missing.

Thirty-five years into the epidemic, there wasn't one data point, factoid or even an asterisk about how the HIV epidemic affects the trans community.

For the trans advocates, especially those of color, who came from all over the country to experience this gathering of the AIDS hive mind, this oversight felt like a punch in the gut.

"I couldn't believe it," says Tiommi J. Luckett, a national board member of Positively Trans (T+) and a Black trans woman living with HIV. "He was talking about cisgender people and Black people, but transgender people never came up."

She adds, "I could feel myself getting angrier and angrier. But I didn't want to be disruptive, so I left. I needed to get out of there."

Achim Howard was sitting next to Luckett and noticed how emotional his "work wife" had become over this presentation. Shaking, Howard knew that although his dear friend didn't want to cause a scene, he had no problem at all doing just that.

"I do this work every day, and to not have any trans representation in those slides—it was a slap in the face," recalls Howard, a DC native who tested HIV positive in 2011.

So, in tears, Howard along with four other trans advocates—Bré Anne Campbell, Octavia Lewis, Francesca Schumann and Carmarion Anderson—stormed the stage.

Although they respectfully waited for the presenter to finish, when he was handed a mic, Howard wasn't as accommodating. He unleashed: "It is not right! We are human beings! We are out here dying too!"

Their rage wasn't just about this presentation. This pushback was a culmination of decades of communal frustration, which continues to explode in ostensibly "safe spaces" like USCA.

"We took that stage to let everyone know that the leaders are the ones people expect to set the tone," explains Lewis, who was diagnosed with HIV in 2006.

She adds, "If you don't have full representation and [if those in power] overlook that the trans community is affected by this epidemic, you are sending the message that our lives don't matter."

Why does this erasure persist, especially since mainstream trans visibility is arguably at an all-time high?

Actresses such as Laverne Cox and recently elected politicians Danica Roem and Andrea Jenkins have enjoyed moments in the national spotlight. Plenty of trans kids are coming out these days. And with 2017 making history as one of the deadliest years to be a trans woman of color, trans people seemed to be in the news or on TV more than ever. But visibility doesn't guarantee sensitivity—even in the HIV/AIDS community.

"There seems to be this misconception that leaders in the HIV/AIDS world and researchers who work in federal agencies are more in tune to the community's needs and are more progressive. That's not necessarily true," says Jenna Rapues, MPH, interim director of San Francisco's Center of Excellence for Transgender Health.

As we embark on 2018, how can we make that misconception a reality? Further, reflecting on what happened at USCA 2017, what do cisgender folks in the movement need to do to empower, uplift and amplify trans voices for generations to come?

From left: Carmarion Anderson, NMAC executive director Paul Kawata, Achim Howard, Octavia Lewis (and her son), Bré Anne Campbell and Francesca Schumann at a USCA 2017 protestCourtesy of Mark S. King

One thing we can all agree on is that trans people, especially Black and Latina trans women, have many risk factors for HIV, such as survival sex, homelessness, economic disparities, trauma, violence and transphobia, and higher rates of the virus as a result.

Yet when it comes to more specific HIV data about trans populations, there's simply not a lot out there.

That lack of robust numbers can be traced back to the Centers for Disease Control and Prevention (CDC), which for decades has been putting trans women into the category of men who have sex with men (MSM) and placing trans men with cisgender women.

"This doesn't make any damn sense," says Howard, founder of DC Trans Men Rising and a Positively Trans board member.

"There's a huge difference between gender identity and sexual orientation," he says. "I am not a woman, so why am I being labeled as one?"

But to hear the CDC tell it, the agency has been making some improvements on this front.

CDC spokesperson Donnica Smalls told POZ in an email that the federal agency has been working with state and local health departments and health care providers "to meet the needs for more reliable data on HIV among transgender people." In addition, the agency is allowing for HIV data to be reported for both sex at birth and current gender identity.

Sounds good, right? Not so fast. When asked whether the CDC has finally stopped misclassifying trans folks, the answer was no.

“HIV diagnoses for transgender people are reported as sex at birth within CDC’s HIV Surveillance Report. Diagnoses for transgender women are currently reported as men who have sex with men, and diagnoses for transgender men are currently reported as cisgender women (female at birth).”

Smalls says that this is because “information on gender identity is not consistently collected or documented in the data sources.” However, the CDC does conduct “separate analyses to present HIV data among transgender people in the United States.”

This enrages Luckett. Although she agrees that data collection isn’t easy, having worked with the Transgender Law Center on its groundbreaking Positively Trans Survey, she knows firsthand that doing this research and correctly classifying trans people is possible, especially if one has the resources and conviction to do so. (See the sidebar on page 37 for data from this and other surveys.)

“We are living proof of the data,” Luckett says. “We reached our community. We did it by being smart and brainstorming and going to the places that the CDC wouldn’t go. And we still got our numbers and labeled everyone correctly. Why can’t they?”

She adds, “The CDC has had years to get it right. I’m just tired of their excuses.”

Rapues, of the Center of Excellence for Transgender Health, says, “This lack of data says a lot about the institutional oppression of trans people in general that proves to be a major problem in our federal agencies, which at times are either working from a transphobic framework or just can’t get their heads around the ‘T’ of ‘LGBT.’”

Either way, Rapues is very clear: “They really ought to be ashamed.”

Proper data collection is vital for the trans population, and not just because it’s important that the data be included in the public record. Data also translate into who gets funding, which prevention programs get prioritized and which public campaigns get launched.

“It’s the chicken-or-the-egg scenario,” says Lewis, one of the activists who stormed the USCA stage and an advisory board member for the Center of Excellence. “The CDC and other funders won’t give you money if the data is not there, but we need the funds to do the data. Yes, the CDC is giving more money for trans HIV-related programs, but it’s not enough. We need more because we know that our people are out there dying.”

But even with the work that’s being done, if reaching trans women is uniquely challenging, reaching HIV-positive trans men can be especially so. But they are out there.

Marcus Ecks, a Black trans man who tested positive for the virus in 2014, believes that for the CDC and local health care providers to include trans people in their surveys and data collection, they must be sure to ask the right questions about risk factors and identity—and do so in a way that isn’t off-putting.

Ecks recalls taking a survey about HIV risk factors. “I was in a long-term relationship with a trans woman, but the survey only asked questions about cis men and cis women, gay or straight.” The 33-year-old was taken aback by the disregard for his identity and experience.

“The terminology didn’t fit, and it was confusing and hard to fill out that survey. How many other trans folks were turned off and didn’t fill it out? Think about all the people who go uncounted because of these types of questions.”

Howard agrees and emphasizes that the lack of data and inclusive surveys further isolate trans men living with HIV. It also exacerbates stigma.

“When I first tested positive, I thought I was the only one. I didn’t see myself reflected in the data, and I also didn’t see myself in any campaigns or see other positive trans men speaking out,” he says. This prompted him to step out on faith in an attempt to fill that void.

“As I put myself out there sharing my story, other positive trans men have come to me saying they never thought they were at risk or that after they were diagnosed they felt alone. It’s obvious that we have a lot more work to do.”

Achim HowardJonathan Timmes

To best advocate for inclusive data, substantial increases in funding and stronger trans leadership, advocates need to address how the intersections of transphobia, racism, sexism, classism and ableism in the HIV community harm trans folks.

As viewed from the outside, the AIDS community might appear to be a diverse snapshot of the marginalized. But a closer look makes clear that white (male cisgender) privilege often plays a huge factor in who and what gets prioritized.

Lewis is quick to point out the irony. “[In the early days] ACT UP built its entire movement on rage and demanding to be recognized and seen. They were ‘passionate’ and ‘brave,’ but when Black trans folks do that now, demand data, we’re called ‘angry’ or accused of having an ‘attitude’ or

that we feel entitled to extra rights," she explains.

Advocates stress how important it is for cis leaders to check their own privilege, to be willing to have the difficult conversations about their own biases and to be better allies, but there is also a consensus that cis leaders need to leverage their privilege to truly advocate for trans people.

For example, Lewis explains, cis folks could ensure that trans issues get brought up in every room they enter.

"If you are really passionate about trans rights," she says, "you need to be a voice for the people who can't be at the table. Even better, demand that there be trans people present advocating for themselves—and not just the tokenized ones but the ones who will speak the truth.

"Also, learn how to close your mouth, let trans people talk and stop policing these spaces because you don't feel comfortable."

Howard adds that leveraging privilege also means that those who run AIDS service organizations and LGBT groups should stop doing trans work without including trans people.

"There are plenty of organizations that will accept funding to do trans work but won't have any trans people leading the cause or even working in their office," he says. "They'll eat off us but won't include us in work that actually affects us."

He adds, "You can't have white people leading Black Lives Matter and not having any Black people involved. But this situation is happening every day with trans folks in the HIV community."

Advocates say that if a true shift in power is going to take place on a systemic and organizational level, then trans folks need to have access to higher-level jobs to attain more power. But in that regard, they also face obstacles.

"A lot of these higher-up jobs require MPH [master of public health] degrees, so trans folks who lack these degrees, who have been doing this work for years, get boxed out," Lewis explains.

"We need to rid ourselves of these educational requirements and foster trans leadership [because] trans folks can do more for your organization than be the administrative assistant."

One thing is certain: Cis leaders and advocates in the HIV community face serious questions.

Will the trans protest at USCA 2017 fall on deaf ears only to need to be repeated this year? Will you consciously do better by HIV-positive trans folks who have fought in the trenches for everyone else?

Most important, are you willing to recognize that none of you can be free if trans people aren't?

Kellee Terrell is the former associate editor of POZ. Her articles and interviews have appeared in Vogue, Harper's Bazaar, Al Jazeera, Essence, Ebony, The Advocate and Hello Beautiful, as well as

TheBody.com.

By the Numbers

5X

1.4% of respondents to the 2015 U.S. Transgender Survey by the National Center for Transgender Equality (NCTE) were living with HIV. That’s nearly five times the rate of the U.S. population (0.3%).

1 in 5

HIV rates were higher among trans women (3.4%), especially those of color, in the NCTE survey. Nearly one in five (19%) Black trans women were HIV positive.

41%

The percentage of respondents to the Positively Trans Survey by the Transgender Law Center (TLC) who had ever gone more than six months without medical care since their HIV-positive diagnosis.

53%

The percentage of respondents to the TLC survey who had ever gone more than six months without medical care who had a provider refuse care because the respondent was living with HIV. Eighty-two percent of those without care for six months were not sure whether they were refused because of having HIV.

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