Speaking With a Collective Voice

In launching a new grassroots network, Latinx people living with HIV define their own agenda.

September 28, 2020 By Joe Mejía

The ethos of LatinX+ is evident in the organization's name. For starters, there's the modern-day gender-neutral/nonbinary "Latinx." The term is as an alternative to Latino/a that emphasizes inclusion and is increasingly being embraced by young and queer people and left-leaning activists.

Then there's the "+," which signals HIV positive, yes, but also communicates the concept of más, meaning "plus," as in addition, or "more," in Spanish. LatinX+ concerns itself with more than just HIV among Latinos; the new group seeks to address such intersecting issues as stigma, criminalization and immigration.

LatinX+ is a grassroots network of predominantly HIV-positive advocates from across the United States and Puerto Rico formed in 2019 with the stated mission to speak with a collective voice on a variety of issues relevant to Latinos living with HIV. In deference to the fact that the Latino community is not a monolith, the group's founding members represent numerous Latin American countries, including Colombia, Honduras and Mexico, either by birth or heritage, and they hail from various states as well as Puerto Rico.

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What’s more, members include men and women, veteran activists and younger advocates, queer and heterosexual people, and cisgender and transgender people. Although logistics, such as geography and limited resources—not to mention the ongoing COVID-19 pandemic—have reduced the members’ in-person face time with one another, LatinX+ nevertheless continues to work to define its agenda in an effort to ultimately improve the lives of Latinos with HIV and stem the spread of the virus among those who are HIV negative.

The group has a nonhierarchical organizational structure reflective of its collective nature and mission. LatinX+ has no executive director or president, for example, but rather consists of a board of members with individual specialties honed from years working on the front lines of the HIV/AIDS epidemic in the Latino community and in most cases from their lived experience as people with HIV. These include specialized advocates for immigration, youth and women, among others, with day jobs working for groups as varied as Positive Women’s Network–USA and Equality Florida.

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In February 2019, the group convened for a two-day strategic retreat in Milford, Pennsylvania, with financial support from the Sero Project, the anti–HIV criminalization group started by POZ founder Sean Strub, and from Equality Florida, the largest civil rights organization for Florida’s LGBT community.

Strub is also the mayor of Milford. He and his partner, LatinX+’s media advocate, Xavier Morales, have called the quaint town home for decades. In 1994, Morales helped Strub found POZ

magazine. In 1997, Morales also assisted in the launch of POZ en Español along with Gonzalo Aburto, a fellow LatinX+ member who served as editor-in-chief of the Spanish-language magazine, which published until 2003.

Morales, who is Puerto Rican, says the idea for the group originated after examining the HIV/AIDS landscape and realizing that Latinos lacked a network with a self-defined agenda. Such a network for Latinos, he and the other members agreed, could address the full spectrum of issues of concern for this community, chief among them HIV stigma and its much more dangerous incarnation, HIV criminalization, as well as immigration. (HIV criminalization refers to the broad use of criminal law to penalize alleged, perceived or potential HIV exposure; alleged nondisclosure of HIV status prior to sexual contact; or nonintentional HIV transmission.)

In an era when it may seem as though everyone knows how not to contract the virus, Morales says, the stigma attached to an HIV diagnosis is at an all-time high. In the early days of the HIV/AIDS epidemic, a community emerged and embraced newly diagnosed people. Today, however, support isn't always readily available to guide people toward acceptance of their new positive status.

Paradoxically, the availability of effective antiretroviral treatment for the virus since the mid-1990s might have played a role in this diminishing support. That's because getting started on treatment very soon after a diagnosis leads to better long-term health outcomes. This fact may have caused health care workers to focus on getting people with HIV on meds, resulting in prioritizing their viral loads and CD4 counts over their psychological well-being and self-acceptance.

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The degree to which the everyday experiences of Latinos remain largely invisible factored into the formation of LatinX+, says Mexico-born and New York City–based Aburto, who serves as the group's international affairs advocate and the director of the Sero Project's Latin America initiative. This invisibility persists despite the fact that in 2019 Latinos represented 18% of the total U.S. population.

What's more, Latinos constitute the country's second largest racial/ethnic group behind non-Hispanic whites. This lack of visibility extends to HIV/AIDS, argues Aburto, specifically, in what he terms "the AIDS industry," by which he means the many larger, more established national groups that enjoy the lion's share of funds and influence in the HIV/AIDS nonprofit sector.

"As gay Latinos, we don't have any organizations that can lead the way to demand what we need," he says. Lacking such an organization, the needs of Latino men who have sex with men, who have a particularly high risk of contracting HIV, are not being met.

One of the new network's goals, says Aburto, is to educate Latinos about HIV by amplifying both past Latino voices and current social issues. This is to remind people of the place Latinos have occupied in HIV history as well as to stress to young Latinos that HIV is very much a part of their present-day experience.

“We must never forget that the roots of the AIDS activist movement included powerful and fierce Latinx advocates like Sylvia Rivera, Pedro Zamora and others who have been drowned and forgotten by mainstream histories. We need to make sure we create a new narrative when it comes to HIV,” Aburto stated on the occasion of LatinX+’s launch.

Aburto has long been preoccupied with shaping this narrative for Latinos affected by HIV. But, he laments, much remains unchanged.

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Latino invisibility comes at a steep price. For one, it contributes to the aforementioned stigma. The less willing that HIV-positive Latinos are to share their stories about living with the virus, the more likely that shame will become inextricably linked with a positive diagnosis. This discourages people from getting tested and starting treatment, which helps explain why, once diagnosed, Latinos tend to present with more advanced HIV disease than whites.

Stigma also interferes with adherence to antiretrovirals, leading to poorer health outcomes among Latinos when they do start treatment. Compared with whites, Latinos die of causes related to HIV at much greater rates. In 2016, the Department of Health and Human Services Office of Minority Health reported that Latino men are twice as likely as non-Latino white men to die of HIV-related causes, while Latinas are three times as likely as non-Latina white women to do so.

According to the latest Centers for Disease Control and Prevention HIV Surveillance Report, Latinos accounted for 26% of total new HIV diagnoses in 2018. In addition, the rate of HIV diagnoses among Latinos was the second highest among all racial or ethnic groups, at 16.4 new cases per 100,000 people, compared with 4.8 per 100,000 among whites—nearly four times higher. (The highest rate was 39.2 per 100,000 for Blacks/African Americans.) The good news is that HIV rates have declined among Latinas; however, this contrasts with a 30% increase among Latino men who have sex with men since 2010.

What’s more, Latino men ages 25 to 34 experienced a 68% rise in new HIV cases, and roughly 25% of trans Latinas are living with HIV. Intersectional stigma, that is, the stigmatization of multiple identities (gay, trans, Latino, immigrant), bears some blame for such statistics.

Driving up testing rates among Latinos is key to combating the HIV epidemic. After all, one in six Latinos don’t know they have the virus, compared with one in eight in the overall population who don’t know their HIV status.

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On the subject of HIV stigma, LatinX+'s Caribbean patient advocate member Rosa Rivera Avilés, who is Puerto Rican, believes much more work needs to be done. She notes that there is a marked difference between tolerance, which she sees as a passive attitude, and acceptance, which requires that people more actively consider and respect those living with HIV. Not only that, external stigma is all too often internalized, and "being in the HIV closet," Rivera Avilés says, "limits access to services."

As an example, she cites the recent death of a 33-year-old Puerto Rican man, who despite having had an aunt who is an infectious disease doctor, didn't discuss his diagnosis with anyone until he wound up in the hospital with no available treatment options. Rivera Avilés is critical of those who say that thanks to effective antiretroviral treatment, HIV is merely another chronic disease; she points out that unlike, say, diabetes, HIV can, for many people, pose an "untenable burden of stigma."

On a broader level, HIV stigma and an ignorance of current science wind up codified in the form of laws that criminalize potential exposure to HIV. These laws are used to prosecute people who don't disclose their HIV status before sex. This results in criminal charges such as reckless endangerment or battery and also takes the form of HIV-specific sentence enhancements that increase penalties for people with HIV convicted of other crimes.

This is regardless of whether HIV transmission has occurred, which it seldom does. In fact, according to the Sero Project's Strub, transmission occurs in less than 5% of such cases. Furthermore, to be liable for such prosecution, those accused must have been tested and know that they are positive, which, Strub points out, "privileges the ignorance of not knowing one's status."

Such laws disregard the current science that has proved that people with HIV who adhere to their antiretroviral treatment regimens and maintain an undetectable viral load cannot transmit the virus sexually, a concept known as Undetectable Equals Untransmittable, or U=U. As of 2019, 34 states had such laws on their books, putting people with HIV in legal jeopardy for nondisclosure despite the fact that they can't transmit the virus. LatinX+ works closely with the Sero Project to modernize such laws and help defend those prosecuted under them. In addition to fighting the criminalization of HIV, Rivera Avilés, who serves on the Ryan White Planning Group and the Advisory Committee for the AIDS Drug Assistance Program (ADAP), is also executive director of the HIV group Movimiento en Respuesta al VIH.

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For Rivera Avilés, LatinX+ presented an opportunity to work with fellow Spanish-speaking colleagues to better serve non-English-speaking Latinos, particularly in Puerto Rico, which, despite being a U.S. territory, she says is often left out of national discussions about HIV. The island has an HIV rate of 15.6 new cases per 100,000 people compared with the overall U.S. rate of 11.5 per 100,000. Additionally, over the years, Rivera Avilés noticed that some of the organizations working on behalf of Latinos didn't seem to have Spanish-speaking members. English is not her primary

language, and she sometimes finds herself at HIV/AIDS conferences with no translators in attendance.

This would seem to be an oversight for groups seeking to serve Spanish-speaking immigrants, especially considering that 42% of foreign-born people diagnosed with HIV from 2007 to 2010 in the United States were Latino, many of whom, presumably, do not speak English.

Among these immigrants are many fleeing their native Latin American countries for fear of persecution for being gay or HIV positive or trans. Even after leaving their own countries and arriving at the U.S.-Mexico border, some immigrants, notably trans Latinas, continue to be persecuted.

With several Spanish-speaking trans members on its board, LatinX+ may be uniquely suited to wage a battle against the mistreatment of trans immigrants at the southern border. Although Morales says the group currently lacks the resources to have a physical presence there, he foresees LatinX+ expanding its efforts to include advocating for HIV-positive people seeking asylum. He mentions two HIV-positive trans Latinas who died under suspicious circumstances while in the custody of the Department of Homeland Security's Immigration and Customs Enforcement agency, or ICE.

One, Roxsana Hernandez, who was seeking asylum from Honduras and was experiencing AIDS-related complications, may have been physically abused before her death in May 2018. Another trans woman, El Salvadoran Johana Medina León, might have been denied medical treatment for complications arising from her lack of access to her antiretroviral medications, resulting in her death on June 1, 2019. ICE maintains her death was caused by cardiac arrest.

These stories have not garnered much coverage from the mainstream press, so LatinX+ shares them to raise awareness among the public. The group also engages with policy and decision makers at the national level with regard to HIV-positive asylum seekers.

ICE has 20,000 law enforcement and support personnel throughout the world and an annual budget of $8 billion. While some progressive Democrats have called for the abolition of ICE, President Trump has doubled-down, removing some formal restraints on the agency. Currently, there are 35,000 immigrants in detention in the United States, mostly in ICE centers. This election year, immigration reform is a priority for many activists, but even more is at stake.

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As the COVID-19 pandemic has underscored, numerous health disparities negatively impact Latinos. Of course, those in the HIV/AIDS community have long been aware of such inequities. But the increased awareness may bring about some needed health care reform.

LatinX+'s Dianne Michelle Trinidad Ramos, the group's Caribbean transgender advocate who also serves on the ADAP Advisory Committee for the Ryan White HIV/AIDS Program and works to promote the U=U message in Puerto Rico, emphasizes that voters should consider which

candidates will work to preserve benefits such as Medicare and housing assistance.

Medicare is of particular concern to people who, like Trinidad Ramos, are aging with HIV. About half of people with diagnosed HIV in the United States are over age 50, and this population experiences comorbidities, such as heart disease and kidney problems, at higher rates than the overall population, possibly driven by the inflammation caused by HIV.

The LatinX+ website (LatinxPlus.com) seeks to educate the community about electoral issues by steering users to the resources of UnidosUS, which serves Latinos via research, policy analysis and advocacy efforts. UnidosUS champions the proposed Health Equity and Accountability Act of 2020, which would address the intersection of health disparities with immigration status, age, disability, sex, gender, sexual orientation, gender identity, language and socioeconomic status. It aims to increase federal funding for health care services for people of color living with HIV/AIDS; improve health care access for all, including undocumented children and families; and strengthen health data collection to inform policies to eradicate racial health disparities.

If LatinX+'s agenda seems vast, that's because it is. After all, the network is looking to fill what it sees as a huge void in the HIV/AIDS landscape, one that has persisted for decades. Not only that, LatinX+ is advocating for Latinos living with HIV from a holistic perspective. The group's viewpoint takes into account the intersecting factors that define the experience of Latinos with HIV. That's ambitious, to say the least, but also critical at a time when people are increasingly recognizing the role of race/ethnicity and socioeconomic and immigration status in health outcomes.

All that said, since Latinos represent about 20% of the total population of 1.2 million people with HIV in the United States—roughly 240,000 people—there may be no better time for a nascent network such as LatinX+ to come into its own and take its rightful seat at the table.

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