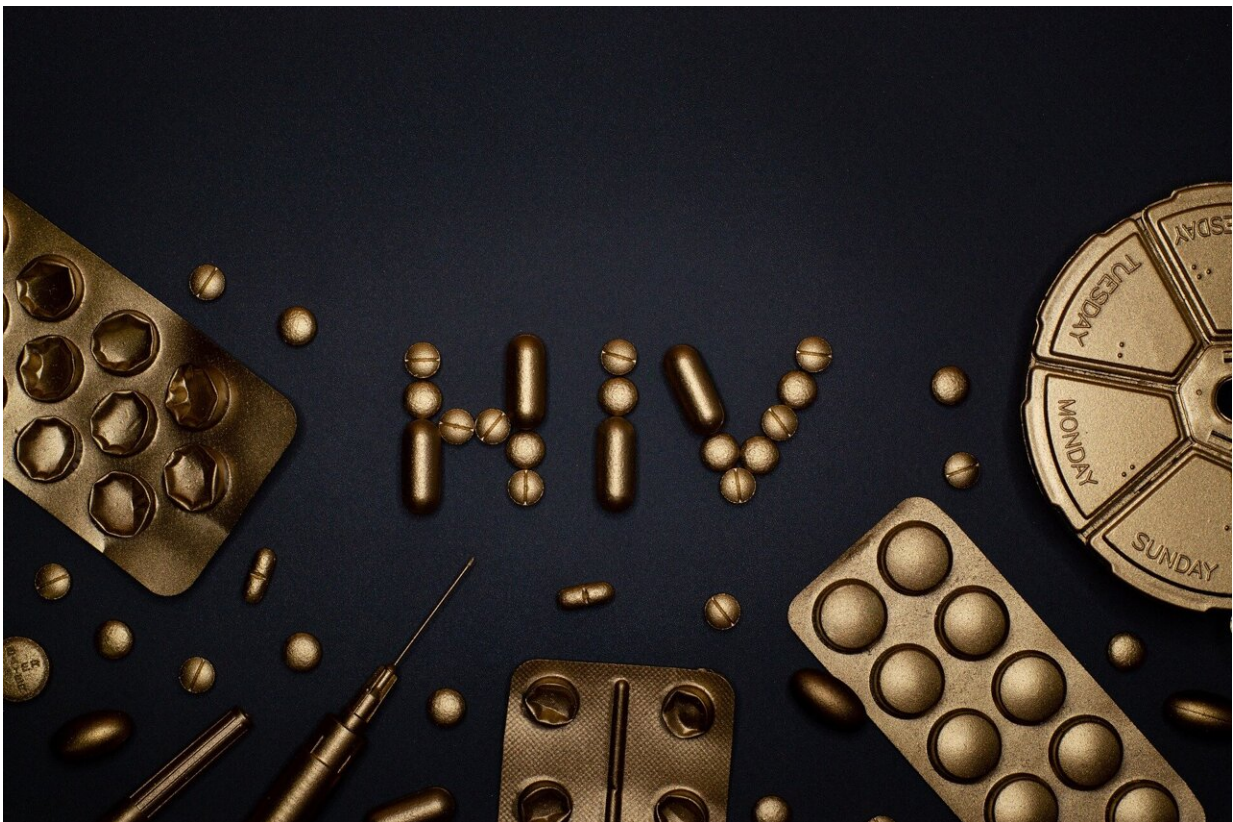


Young gay Latinos see rising share of new HIV cases, leading to call for targeted funding

June 27 2024, by Vanessa G. Sánchez and Devna Bose, Associated Press and Phillip Reese, KFF Health News



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Four months after seeking asylum in the U.S., Fernando Hermida began

coughing and feeling tired. He thought it was a cold. Then sores appeared in his groin and he would soak his bed with sweat. He took a test.

On New Year's Day 2022, at age 31, Hermida learned he had HIV.

"I thought I was going to die," he said, recalling how a chill washed over him as he reviewed his results. He struggled to navigate a new, convoluted health care system. Through an HIV organization he found online, he received a list of medical providers to call in Washington, D.C., where he was at the time, but they didn't return his calls for weeks. Hermida, who speaks only Spanish, didn't know where to turn.

By the time of Hermida's diagnosis, the U.S. Department of Health and Human Services was about three years into a federal initiative to end the nation's HIV epidemic by pumping hundreds of millions of dollars annually into certain states, counties, and U.S. territories with the highest infection rates. The goal was to reach the estimated 1.2 million people living with HIV, including some who don't know they have the disease.

Overall, estimated new HIV infection rates declined 23% from 2012 to 2022. But a KFF Health News-Associated Press analysis found the rate has not fallen for Latinos as much as it has for other racial and [ethnic groups](#).

While African Americans continue to have the highest HIV rates in the United States overall, Latinos made up the largest share of new HIV diagnoses and infections among gay and bisexual men in 2022, per the most recent data available, compared with other racial and ethnic groups. Latinos, who make up about 19% of the U.S. population, accounted for about 33% of new HIV infections, according to the Centers for Disease Control and Prevention.

The analysis found Latinos are experiencing a disproportionate number of new infections and diagnoses across the U.S., with diagnosis rates highest in the Southeast.

Public health officials in Mecklenburg County, North Carolina, and Shelby County, Tennessee, where data shows diagnosis rates have gone up among Latinos, told KFF Health News and the AP that they either don't have specific plans to address HIV in this population or that plans are still in the works. Even in well-resourced places like San Francisco, California, HIV diagnosis rates grew among Latinos in the last few years while falling among other racial and ethnic groups despite the county's goals to reduce infections among Latinos.

"HIV disparities are not inevitable," Robyn Neblett Fanfair, director of the CDC's Division of HIV Prevention, said in a statement. She noted the systemic, cultural, and economic inequities—such as racism, language differences, and medical mistrust.

And though the CDC provides some funds for minority groups, Latino health policy advocates want HHS to declare a public health emergency in hopes of directing more money to Latino communities, saying current efforts aren't enough.

"Our invisibility is no longer tolerable," said Vincent Guilamo-Ramos, co-chair of the Presidential Advisory Council on HIV/AIDS.

Lost without an interpreter

Hermida suspects he contracted the virus while he was in an open relationship with a male partner before he came to the U.S. In late January 2022, months after his symptoms started, he went to a clinic in New York City that a friend had helped him find to finally get treatment for HIV.

Too sick to care for himself alone, Hermida eventually moved to Charlotte, North Carolina, to be closer to family and in hopes of receiving more consistent health care. He enrolled in an Amity Medical Group clinic a federal safety-net plan that serves over half of those in the nation diagnosed with HIV, regardless of their citizenship status.

His HIV became undetectable after he was connected with case managers. But over time, communication with the clinic grew less frequent, he said, and he didn't get regular interpretation help during visits with his English-speaking doctor. An Amity Medical Group representative confirmed Hermida was a client but didn't answer questions about his experience at the clinic.

Hermida said he had a hard time filling out paperwork to stay enrolled in the Ryan White program, and when his eligibility expired in September 2023, he couldn't get his medication.

He left the clinic and enrolled in a health plan through the Affordable Care Act marketplace. But Hermida didn't realize the insurer required him to pay for a share of his HIV treatment.

In January, the Lyft driver received a \$1,275 bill for his antiretroviral—the equivalent of 120 rides, he said. He paid the bill with a coupon he found online. In April, he got a second bill he couldn't afford.

For two weeks, he stopped taking the medication that keeps the virus undetectable and intransmissible.

"Estoy que colapso," he said. I'm falling apart. "Tengo que vivir para pagar la medicación." I have to live to pay for my medication.

One way to prevent HIV is preexposure prophylaxis, or PrEP, which is

regularly taken to reduce the risk of getting HIV through sex or intravenous drug use. It was approved by the federal government in 2012 but the uptake has not been even across racial and ethnic groups: CDC data show much lower rates of PrEP coverage among Latinos than among white Americans.

Epidemiologists say high PrEP use and consistent access to treatment are necessary to build community-level resistance.

Carlos Saldana, an infectious disease specialist and former medical adviser for Georgia's health department, helped identify five clusters of rapid HIV transmission involving about 40 gay Latinos and men who have sex with men from February 2021 to June 2022. Many people in the cluster told researchers they had not taken PrEP and struggled to understand the [health care system](#).

They experienced other barriers, too, Saldana said, including lack of transportation and fear of deportation if they sought treatment.

Latino health policy advocates want the federal government to redistribute funding for HIV prevention, including testing and access to PrEP. Of the nearly \$30 billion in federal money that went toward things like HIV health care services, treatment, and prevention in 2022, only 4% went to prevention, according to a KFF analysis.

They suggest more money could help reach Latino communities through efforts like faith-based outreach at churches, testing at clubs on Latin nights, and training bilingual HIV testers.

Latino rates going up

Congress has appropriated \$2.3 billion over five years to the Ending the HIV Epidemic initiative, and jurisdictions that get the money are to

invest 25% of it in community-based organizations. But the initiative lacks requirements to target any particular groups, including Latinos, leaving it up to the cities, counties, and states to come up with specific strategies.

In 34 of the 57 areas getting the money, cases are going the wrong way: Diagnosis rates among Latinos increased from 2019 to 2022 while declining for other racial and ethnic groups, the KFF Health News-AP analysis found.

Starting Aug. 1, state and local health departments will have to provide annual spending reports on funding in places that account for 30% or more of HIV diagnoses, the CDC said. Previously, it had been required for only a small number of states.

In some states and counties, initiative funding has not been enough to cover the needs of Latinos.

South Carolina, which saw rates nearly double for Latinos from 2012 to 2022, hasn't expanded HIV mobile testing in rural areas, where the need is high among Latinos, said Tony Price, HIV program manager in the state health department. South Carolina can pay for only four community health workers focused on HIV outreach—and not all of them are bilingual.

In Shelby County, Tennessee, home to Memphis, the Latino HIV diagnosis rate rose 86% from 2012 to 2022. The health department said it got \$2 million in initiative funding in 2023 and while the county plan acknowledges that Latinos are a target group, department director Michelle Taylor said, "There are no specific campaigns just among Latino people."

Up to now, Mecklenburg County, North Carolina, didn't include specific

targets to address HIV in the Latino population—where rates of new diagnoses more than doubled in a decade but fell slightly among other racial and ethnic groups. The health department has used funding for bilingual marketing campaigns and awareness about PrEP.

Moving for medicine

When it was time to pack up and move to Hermida's third city in two years, his fiancé, who is taking PrEP, suggested seeking care in Orlando, Florida.

The couple, who were friends in high school in Venezuela, had some family and friends in Florida, and they had heard about Pineapple Healthcare, a nonprofit primary care clinic dedicated to supporting Latinos living with HIV.

The clinic is housed in a medical office south of downtown Orlando. Inside, the mostly Latino staff is dressed in pineapple-print turquoise shirts, and Spanish, not English, is most commonly heard in appointment rooms and hallways.

"At the core of it, if the organization is not led by and for people of color, then we're just an afterthought," said Andres Acosta Ardila, the community outreach director at Pineapple Healthcare, who was diagnosed with HIV in 2013.

"¿Te mudaste reciente, ya por fin?" asked nurse practitioner Eliza Otero. Did you finally move? She started treating Hermida while he still lived in Charlotte. "Hace un mes que no nos vemos." It's been a month since we last saw each other.

They still need to work on lowering his cholesterol and blood pressure, she told him. Though his viral load remains high, Otero said it should

improve with regular, consistent care.

Pineapple Healthcare, which doesn't receive initiative money, offers full-scope primary care to mostly Latino males. Hermida gets his HIV medication at no cost there because the clinic is part of a federal drug discount program.

The clinic is in many ways an oasis. The new diagnosis rate for Latinos in Orange County, Florida, which includes Orlando, rose by about a third from 2012 through 2022, while dropping by a third for others. Florida has the third-largest Latino population in the U.S., and had the seventh-highest rate of new HIV diagnoses among Latinos in the nation in 2022.

Hermida, whose asylum case is pending, never imagined getting medication would be so difficult, he said during the 500-mile drive from North Carolina to Florida. After hotel rooms, jobs lost, and family goodbyes, he is hopeful his search for consistent HIV treatment—which has come to define his life the past two years—can finally come to an end.

"Soy un nómada a la fuerza, pero bueno, como me comenta mi prometido y mis familiares, yo tengo que estar donde me den buenos servicios médicos," he said. I'm forced to be a nomad, but like my family and my fiancé say, I have to be where I can get good medical services.

That's the priority, he said. "Esa es la prioridad ahora."

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