# AlDSWatch

# POLICY BRIEF

AIDSWatch — hosted by AIDS United, the US People Living with HIV Caucus, and the Treatment Access Expansion Project/Center for Health Law and Policy Innovation — is the largest national, constituent-led HIV advocacy event in the country. The event, which began 29 years ago with a small group of dedicated advocates, has transformed and grown, even as the COVID-19 pandemic has upended lives. While there has been tremendous progress since that first AIDSWatch, the need for vigorous HIV advocacy has never been greater: communities impacted by HIV are struggling under the burden of syndemics and their social and economic impacts, but we also now have the scientific knowledge and wider recognition of the racial and social injustices driving the epidemic needed to address barriers blocking our efforts — if we can provide and inspire the political will.

#### While there has been tremendous progress since that first AIDSWatch, the need for vigorous HIV advocacy has never been greater

This year, we find ourselves still in the midst of an ongoing COVID-19 pandemic, worsened by systemic injustices and constant crises. But we also face opportunities for grassroots HIV advocacy to strive for better programming and support that can ultimately improve the quality of life for people living with and vulnerable to HIV.

As <u>networks of people living with HIV have shown and affirmed for decades</u>, our federal HIV response must center the rights of all people living with HIV to health, wellness, dignity and safety. Below are several policy recommendations that, while not an exhaustive list, would put our nation on the path to improving the quality of life for people living with HIV and ending the HIV epidemic.

# **1** Congress must address quality of life issues for people living with HIV

People living with or vulnerable to HIV have unique needs that require highquality, comprehensive health care. Unfortunately, many people lack access to necessary treatments and services. Additionally, the value of our lives extends beyond biomedical markers, and the federal government must recognize the role that other forms of wellness play in supporting people living with or vulnerable

to HIV.

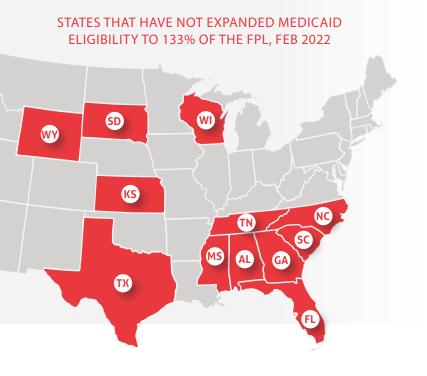
#### Medicaid

Medicaid remains one of the largest sources of health care coverage for people living with HIV. Unfortunately, 12 states have not expanded program eligibility, leaving many low-income, childless adults in the "Medicaid gap" and without access to health care. Additionally, once the Biden administration ends the public health emergency, most Medicaid enrollees will go through an eligibility redetermination process. This process will risk millions of people losing coverage, some due to the logistical challenges of redetermination.



We demand that Congress:

- Secure health care for uninsured individuals and families who cannot get Medicaid because their states have not expanded program eligibility.
- Extend the enhanced federal matching for state Medicaid programs and allow state officials the time and resources to minimize loss of coverage.
- Encourage the Department of Health and Human Services to update federal guidance for state Medicaid programs on the provision of treatment and services for HIV and hepatitis C to reflect recent advances in care.



The Centers for Disease Control and Prevention estimate that over <u>43%</u> of the people living with HIV in the <u>United States experience barriers</u> to the treatment, care and services that would support viral suppression. As <u>undetectable = untransmittable</u> <u>shows</u>, the HIV transmission prevention that results from viral suppression supports community health. The well-being of people living with HIV — supported by broad access to health care and supportive services — is a crucial component of ending the HIV epidemic.

#### **Private Insurance**

The health care marketplace (also known as Healthcare.gov and state exchanges) has been a source of highquality private health care plans for millions of people in the United States. Additionally, many have used enhanced premium tax credits and subsidies to lower the cost of purchasing and using a health care plan.

We demand that Congress:

• Extend enhanced financial assistance for middle- and low-income people buying health care coverage on the health care marketplace, so those experiencing the financial pressures of COVID-19 and those who face disenrollment from Medicaid can turn to the marketplace to secure health care coverage.

#### **HIV Prevention**

We must invest in programs that expand access to HIV prevention. Regular use of preexposure prophylaxis, or PrEP, can <u>reduce the risk of getting HIV</u> through sex by 99% and through injection drug use by 74%. However, many people continue to face barriers when accessing PrEP, including inappropriate cost sharing and stigma.

We demand that Congress:

- Expand access to HIV prevention by increasing funding and coverage of PrEP medication and ancillary services, including for people who are uninsured and for people in private health insurance plans that have incurred inappropriate cost sharing.
- Pass legislation that helps expand access to this important prevention tool and bring us closer to ending the HIV epidemic, such as the <u>PrEP Access and Coverage Act</u> (S. 3295/H.R. 6117) and the <u>PrEP Assistance Program Act</u> (H.R. 5605).

#### Social Determinants of Equity and Health

Our health care system was built on a foundation of institutionalized racism. If we are to end the HIV epidemic, we must dedicate resources to address the <u>social determinants of equity</u>, including but not limited to racism, transphobia, homophobia, xenophobia and ableism. We must examine health programs and consider whether these opportunities are structured in ways that undervalue communities that have historically faced and continue to face oppression, such as chronic underfunding of the Indian Health Service. We must also ensure that our health care financing structures are flexible enough to address the social determinants of health and integrate innovative, effective programming.

We demand that Congress:

- Invest in programs that address the social determinants of equity and health, including efforts to combat COVID-19, improve housing and food security, and expand access to nonemergency medical transportation.
- Pass legislation like the <u>Medically Tailored Home-Delivered Meals Demonstration Pilot Act</u> (H.R. 5370), which establishes a Medicare pilot program that allows hospitals to provide medically tailored meals to people with certain chronic conditions.
- Ensure the federal Ending the Epidemic initiative and other broader health efforts are communitybased, community-tailored and fully funded.

#### **Removing Barriers to Care**

We must make sure lifesaving health care services are accessible to people who might not otherwise interact with health care institutions, particularly as the COVID-19 pandemic continues to exacerbate isolation, loneliness, and mental health struggles. For people who use drugs, syringe services programs are often the only space where they can receive quality, compassionate health care and not feel marginalized and judged. As the United States passes the grim milestone of experiencing more than 100,000 overdose deaths in a 12-month span and with injection drug use-related HIV transmission on the rise, we must act now to remove barriers to care for people who use drugs.



- Ensure that all people living with and vulnerable to HIV have access to quality, affordable, evidence-based mental health and drug user health services.
- Eliminate any language restricting the use of federal funds to purchase syringes and related supplies and support syringe services programs in responding fully to the needs of their clients.

# 2 Congress must address ongoing and persistent unfair and discriminatory practices that perpetuate structural and institutional racism and other inequities

#### **The Equality Act**

The Equality Act would amend existing civil rights laws, including the Civil Rights Act of 1964, to explicitly prohibit discrimination based on sex, sexual orientation and gender identity in a wide variety of areas, including employment, housing, public accommodations, public spaces, services, access to credit and jury service.

This has the potential to reduce the stigma many people face in receiving HIV care services. To end the HIV epidemic, we must limit the stigma that those living with and vulnerable to HIV face on a daily basis. The Equality Act is critical for those who are LGBTQ+ to be able to access critical services that allow individuals to remain in care. Services such as health care, housing and employment are critical to ending the HIV epidemic.

Particularly given the <u>ongoing and intensified legislative attacks</u> on our transgender community members, passing the Equality Act is essential to ensure that sexual and gender-based discrimination does not stand in the way of ending the HIV epidemic.

We demand that Congress:

• Pass the Equality Act (H.R. 5).

#### **Voting Rights**

Nearly every facet of our lives, including our health care and quality of life, is impacted by public policies. These policies are set by elected officials or people appointed by elected officials. Elections have consequences. Each ballot and each vote we cast impacts things like the Affordable Care Act, reproductive rights, expansion of Medicaid in your state or not, and the cost of medications that keep us alive. Voting determines who makes these policy decisions.

Over the past few years, we have seen unprecedented threats to accessing the right to vote and outright efforts to suppress voting. Voting is often riddled with barriers, and more walls are erected every day. Voter suppression is alive and well, and it is growing in strength during each state's legislative session. In 2021, 18 states passed 34 laws restricting access to voting. The trend to restrict access to voting is continuing in 2022.

Passing the John R. Lewis Voting Rights Act and the Freedom to Vote Act will help change this. Making voting more accessible for all makes people from all communities, including marginalized communities, more visible to elected officials. By demanding better of our elected officials, we can ensure that voting becomes a fundamental human right.



- Pass the John R. Lewis Voting Rights Advancement Act (H.R. 4), which would strengthen voting rights by expanding and strengthening the government's ability to respond to voting discrimination particularly toward communities of color. The language of the final bill must preempt any current state legislation that threatens voting rights.
- Pass the <u>Freedom to Vote Act</u> (S. 2747) which includes measures to reform voter registration and voting access, election integrity and security, redistricting, and campaign finance.

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#### **HIV Criminalization**

HIV criminalization laws contribute to people living with HIV being targeted and punished beyond the courtroom. HIV criminalization laws present a deterrent to testing and seeking care. Furthermore, data from several states with HIV criminalization laws provide evidence of racial and gender bias in their prosecutorial application, disproportionately enforced against Black and Latinx gay and bisexual men, cisgender and transgender women, and people who engage in sex work.

Reform or repeal of HIV criminalization laws requires states to act. Federal leadership on the HIV response has a critical and important role to play in creating an affirming legal, social and political climate for people living with and vulnerable to HIV to engage in effective health care and have all their human rights protected.

We demand that Congress:

- Pass <u>The Repeal Existing Policies that Encourages and Allow Legal (REPEAL) HIV Criminalization Act</u> that is consistent with current HIV decriminalization advocates' understanding and strategy and that incentivizes states to reform or repeal their respective laws.
- Enact legislation encouraging and supporting states to repeal HIV criminalization laws.



#### **Gender Justice**

Women, including trans women, account for about a quarter of the domestic HIV epidemic. In 2018 alone, an estimated 7,189 cisgender women and 554 trans women were newly diagnosed with HIV in the United States. The single largest percentage increase in the number of people living with HIV from 2014 through 2018 by gender was among trans women. Gender disparities are also racialized and geographic: Black, Latinx, and other women of color represent a majority of women living with HIV in the United States and a majority of new HIV acquisitions.

- Pass legislation to fund programs led by women and trans people to address housing, the HIV epidemic and other health care needs through a gender equity lens.
- Pass legislation to require grantees to include intimate partner violence screenings in health care supportive service settings.
- Secure funding for Title X family planning program grantees to maintain affordable access to birth control, screenings for cancer and sexually transmitted infections, pregnancy testing.
- Pass the <u>The Equal Access to Abortion Coverage in Health Insurance (EACH) Act</u> (H.R. 2234/S. 1021) which ensurers those who receive health care or health insurance from the government can access abortion coverage.

- Pass the Paycheck Fairness Act (H.R. 7/S. 205) in the Senate to help eliminate the gender wage gap.
- Pass the <u>LGBTQ Data Inclusion Act</u> (H.R. 4176/S. 2287). This bill requires federal agencies that collect demographic information through surveys to review existing data sets to determine where in their work sexual orientation and gender identity data is not included, and to update relevant surveys to include questions regarding sexual orientation and gender identity.
- Pass legislation, such as the <u>Build Back Better Act</u>, that includes paid family leave.

#### **Reproductive Rights**

Unfortunately, when it comes to sexual and reproductive health care, people living with HIV suffer from the high levels of stigma, a lack of understanding and discrimination from health care providers. Yet, people of all genders living with HIV require sexual and reproductive health care. Indeed, high-quality, nonstigmatizing sexual and reproductive health care is crucial for well-being and overall health. Cisgender women living with HIV are frequently not offered or referred for other sexual and reproductive health services when receiving HIV care, despite being at elevated risk for gynecological complications. And it is especially important that trans people living with HIV receive genderaffirming care, and that providers are well-versed on their patients' options and rights. Trans people face high rates of discrimination, stigma and lack of transcompetent care.

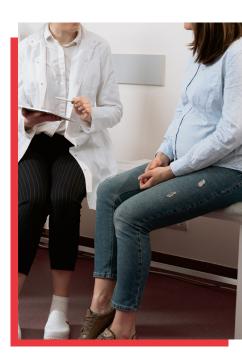
We demand that Congress:

- Pass the <u>HIV Epidemic Loan-Repayment Program (HELP) Act</u> (H.R. 2295), which will help build the next generation of HIV care & prevention experts and address clinical HIV workforce shortages.
- Pass the <u>Medicare For All Act</u> (H.R. 1976) to establish a national health insurance program.

#### Sex Work

Sex workers have long been among the communities most impacted by HIV. A trans woman who has ever done sex work in her lifetime is over 25 times more likely to be living with HIV than the general population. Sex workers are also at increased risk for violence from community and from law enforcement, and bear the brunt of HIV-related prosecutions, convictions and sentence enhancements in many U.S. states and territories. HIV services and government programs may also stigmatize and structurally exclude sex workers. To end the HIV epidemic, competent and nonstigmatizing HIV services must be provided to sex workers, and sex workers must be able to benefit from other publicly funded programs without fear of judgment, criminalization, exclusion or confidentiality violations.

- Pass the <u>SAFE Sex Worker Study Act</u> (H.R. 6928), which would require the National Institutes of Health to conduct a study on the negative health impacts of recent legislation called <u>SESTA/FOSTA</u> on sex workers in our communities.
- Oppose the <u>EARN IT Act</u> (H.R. 6544/S. 3538) and other bills that threaten internet privacy and further criminalize and stigmatize consensual sexual engagement.
- Repeal exclusions and eliminate policies that prevent or hinder individuals with commercial sexand drug-related convictions from applying for or receiving student loans, public housing or housing assistance, public assistance, or other government-funded social services.



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#### Immigrants

Immigrants have been excluded from most health services due to legislative and regulatory exclusions. Even under the Affordable Care Act, millions of undocumented individuals remain unable to access health care and other services that support access to health care. In addition, safety concerns and language injustice persist. Regulatory barriers have been erected to prevent immigrants living with HIV from accessing systems of care they need and have a right to, including health care. These barriers have fueled medical mistrust and service avoidance among immigrant communities.

Immigrants of any legal status and immigrants who do not speak, read or write English must be assured high-quality HIV prevention, care and facilitative services. Immigrants must be able to participate safely and without financial or legal repercussions in HIV programs and must have unfettered access to treatment.

We demand that Congress:

• Pass comprehensive immigration legislation that would cover immigration from all countries such as the following bills:

• The <u>HEAL Act for Immigrant Families</u> (S. 1660), which would extend Medicaid and Children's Health Insurance Program coverage to eligible individuals in the United States.

• The <u>American Dream and Promise Act</u> (H.R. 6) to adjust certain processes for receiving permanent resident status and other immigration reforms.

• The <u>U.S. Citizenship Act</u> (H.R. 1177), which would expand paths to citizenship for some immigrants and updates immigration statutes and processing.

# **3** Congress must accelerate and support efforts to end the HIV epidemic in the US by 2030



#### **Updated National HIV/AIDS Strategy**

On World AIDS Day 2021, the Biden administration released an update to the <u>National HIV/AIDS Strategy</u>, or NHAS, detailing the federal government's objectives and strategies in addressing HIV. Community members have commended the advances made in the update and will continue to hold the administration accountable in the implementation of NHAS and the development of future federal HIV policy. Congress must play its role, too, by approving the president's \$670 million budget request for fiscal year 2022. The sooner Congress invests in these programs that support people living with and vulnerable to HIV, the sooner we will end the epidemic.

The federal government must advance their commitments to ending the epidemic with community, particularly by:

Establish meaningful involvement of people living with HIV and disproportionately impacted communities on agency advisory councils, including designated representation on the President's Advisory Council on HIV/AIDS, the CDC/ HRSA Advisory Council, and the Office of AIDS Research Advisory Council. Acknowledge a minimum standard of care and quality of life for people living with HIV, promulgate regulations requiring health care providers to conform to these standards, and monitor and report how these standards are being upheld.

#### **Appropriations**

Through the appropriation of federal dollars, Congress sets and supports national priorities. To reach the ambitious but achievable goal of ending the domestic HIV epidemic by 2030, Congress will need to join the administration's and community's efforts by increasing investments in public health infrastructure and responses. The AIDS Budget and Appropriations Coalition — a group of over 180 national and community-based HIV and public health organizations — has outlined HIV-specific investments to be made <u>here</u>.

Congress must ensure timely negotiations on fiscal year 2023 appropriations. Extensive continuing resolutions — legislation that Congress can pass to maintain current funding levels to extend funding negotiations and avert shutdowns — can do more harm than good and put long-term funding for the nation's public health programs at risk.

In particular, we demand that Congress fund the following programs at these levels in fiscal year 2023:

- The Ryan White HIV/AIDS Program \$2.942 billion.
- Housing Opportunities for People With AIDS (HOPWA) \$600 million.
- Minority AIDS Initiative \$610 million across programs.
- Ending the Epidemic supplemental funding across programs various amounts (see chart below).
- Opioid-Related Infectious Diseases program within CDC \$150 million.

Years of level funding have left programs serving people living with HIV with strained budgets while the epidemic continues. When Congress extends existing funding levels with *continuing resolutions* instead of appropriating new funds, long-term public health funding is put at risk.



The Ryan White HIV/AIDS Program – \$2.942 billion (a \$447.5 million increase from fiscal year 2022 level) The Ryan White HIV/AIDS Program in the Health Resources and Services Administration provides HIV primary medical care, medications and essential support services for low-income people living with HIV who are uninsured or underinsured. The Ryan White Program is uniquely designed as wraparound care to address the myriad intersecting health issues that people living with HIV often encounter and stands as a model for holistic care 32 years after its creation. Nearly half of people living with HIV in the United States rely on the Ryan White Program for some aspect of their care, and it is a particularly significant source of care for older adults living with HIV, with <u>people over 50 representing 47%</u> of Ryan White clients. However, program funding has not increased to match the pace to provide care to all who would benefit — particularly as more people are tested through the Ending the Epidemic initiatives and know their status.

Housing Opportunities for People With AIDS – \$600 million (a \$145 million increase from fiscal year 2022

#### Health Care & Federal Funding

For years, we have fought for programs, like the Ryan White HIV/AIDS Program, that provide critical medical and support services to people living with HIV. These programs have served as a significant source of care for <u>older adults living with HIV</u> and have helped people from underserved communities reach record rates of viral suppression.

#### level)

Research has shown that housing is the greatest unmet service need for people living with HIV, and the HOPWA program is the only federal funding dedicated to directly addressing this need. Made painfully clear by the COVID-19 pandemic and the subsequent, widespread housing instability, the relationship between housing and health must inform the ways our nation invests in health initiatives. Current HOPWA funding does not meet the need for housing, but the increases requested by the AIDS Budget and Appropriations Coalition would go a long way toward preventing homelessness among people living with and vulnerable to HIV. This funding would also create access to medical care and support services.



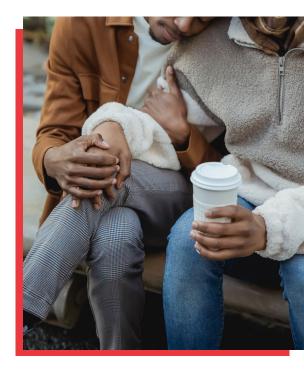


### Minority AIDS Initiative – \$610 million across programs (a \$165.9 million increase from fiscal year 2022 levels)

Communities of color, long impacted by structural racism, must be centered in federal efforts to end the domestic HIV epidemic. The Minority AIDS Initiative is unique funding that promotes collaboration between HHS-funded programs to enhance already existing HIV care. The Minority AIDS Initiative is designed to augment federal spending with complementary programs for and by communities of color most impacted by HIV.

## Ending the Epidemic supplemental funding across programs – various amounts (see chart on next page)

The Ending the HIV Epidemic initiative, announced under the previous administration, represents the most significant and cohesive federal investment to date in the effort to end the domestic epidemic. It is imperative that Congress fully fund the agencies currently involved in the effort while expanding the reach of this innovative, tailored initiative by further funding the involvement of other critical agencies — namely the Department of Housing and Urban Development and the Substance Abuse and Mental Health Services Agency.



## Opioid-Related Infectious Diseases program within CDC – \$150 million (a \$130.5 million increase from fiscal year 2022 levels)

We cannot end the HIV epidemic in the United States if we do not end the overdose epidemic as well. To do this, the federal government must fund evidence-based harm reduction strategies for getting people who use drugs into care and onto a path toward better health outcomes. The public health experts at the CDC understand the importance of harm reduction approaches and of meaningfully involving people who use drugs in their efforts to end the HIV and overdose epidemics. Congressional investment in the opioid-related infectious diseases program will ensure that harm reduction funding goes to community-based organizations led by and for people who use drugs.



#### **Key FY2023 Funding Requests**

Agency	Program	FY2021 Final	FY2022 Final	FY2023 Budget Request	FY2023 ABAC request
HHS	Ryan White Program - total (HRSA)	\$2.424 b (+\$35.0 m)	\$2.555 b (+\$131.0 m)	\$2.655 b (+\$15.0 m)	\$2.942 b (+\$296.0 m)
	Minority AIDS Initiative	TBD*			\$610.0 m (+\$165.9 m)
	Opioid-related infectious disease program (CDC)	\$13.0 m (+\$3.0 m)	\$18.0 m (+\$5.0 m)	\$19.5 m (+\$1.5 m)	\$120 m (+\$102.0 m)
HUD	HOPWA	\$430.0 m (+\$20.0 m)	\$450.0 m (+\$20.0 m)	\$455 m (+\$5.0 m)	\$600 m (+\$170.0 m)

\*Total Minority AIDS Initiative funding is distributed through multiple programs and, in most instances, is included in the funding requests for those programs. Estimated sums of these distributions have not yet been calculated for recent years.

#### Ending the Epidemic **funding across HHS Programs**

Program	FY2021 Final	FY2022 Final	FY2023 Budget Request	FY2023 ABAC Request
Division of HIV Prevention (within CDC)	\$175.0 m (+\$35.0 m)	\$195.0 m (+\$20.0 m)	\$310.0 m (+\$115.0 m)	\$310 m (+\$115.0 m)
Community Health Centers (within HRSA)	\$102.0 m (+\$52.0 m)	\$122.3 m (+\$20.0 m)	\$172.3 m (+\$50.0 m)	\$172.3 m (+\$50.0 m)
Indian Health Services	\$5.0 m (+\$5.0 m)	\$5.0 m (+\$0.0 m)	\$52.0.0 m (+\$47.0 m)	\$52.0 m (+\$47.0 m)
Ryan White Program	\$105.0 m (+\$35.0 m)	\$190.0 m (+\$85.0 m)	\$290.0 m (+\$165.0 m)	\$290.0 m (+\$165.0 m)

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