

AIDSWatch

30 YEARS OF ACCELERATING ACTION

POLICY BRIEF

AIDSWatch is the largest constituent-led HIV advocacy event in the country. For 30 years, those of us living with HIV and our allies have advocated on the state, local and national levels for the policies we know will end the HIV epidemic. At this 30th anniversary AIDSWatch, we continue this advocacy work focusing on policies relating to quality of life, access to health care, civil rights, aging with HIV, HIV decriminalization and federal funding. All of this is in the context of both the COVID-19 pandemic and mpox outbreak, which continue to disproportionately impact our communities. While there has been tremendous progress since that first AIDSWatch, we still need vigorous HIV advocacy.

AIDSWatch is hosted by AIDS United, in partnership with the US People Living with HIV Caucus and the Center for Health Law and Policy Innovation. A core value of the movement is the meaningful involvement of people living with HIV and AIDS, or MIPA for short. These principles ensure that the communities most affected by HIV are involved in decision-making, at every level of the response — and that includes policy. MIPA requires dedication, planning and assessment, institutional buy-in, and champions to help usher its development and continued assessment. This work takes time, but the investment in MIPA is critical, doable and well worth the effort. As AIDSWatch participants today, we urge your offices to more formally implement MIPA values into your work and to maintain connection with your constituents impacted by HIV as experts in the topic. We are happy to be here with you today sharing our knowledge and experiences.

For citations, latest bill numbers of the legislation mentioned and additional information on the policy recommendations discussed here, please scan the following QR code:



SEVEN QUALITY OF LIFE POLICIES

These policy changes will improve the quality of life for people living with HIV.



1 HEALTH CARE ACCESS

Expand Medicaid to improve equitable access to health care. Twelve states have still not expanded Medicaid. In states where Medicaid has been expanded, only 5% of people remain uninsured, compared to the 19% in states where Medicaid has not been expanded. A majority of the states that have not adopted Medicaid expansion are in the South, where approximately 45% of all people living with HIV in the United States reside.



2 HOUSING

Fully fund Housing Opportunities for People with AIDS and other federal housing programs, and enforce the Fair Housing Act to address housing discrimination.



3 MENTAL HEALTH AND SUBSTANCE USE DISORDER SERVICES

Supporting the health and well-being of people living with HIV means supporting their mental health as well as their physical health. Affordable and equitable access to evidence based mental health and substance use disorder is essential to improving the quality of life of people living with HIV.



4 SUPPORTIVE SERVICES

Facilitate other supports that allow health care to be truly accessible such as child care and transportation.



5 ACCESS TO QUALITY FOOD

Food assistance programs are critical for people living with HIV to receive proper nutrition, which in turn supports overall health, helps with immune system function and can help maintain a healthy weight, which helps with the absorption of HIV medicines. Reducing the stress associated with food insecurity also improves the overall quality of life for people living with HIV.



6 EMPLOYMENT

Support economic justice and employment for people living with HIV. People living with HIV must be able to live without negative employment or economic consequences related to their health status, disability, sex, gender or gender expression, sexual orientation, family responsibilities, and race or ethnicity.



7 REPRODUCTIVE CHOICES

Many factors lead to a lack of access to equitable reproductive care, but often the prohibitive costs of health care, stigmatizing experiences in health care settings and discrimination are to blame. Culturally relevant, nonstigmatizing, and comprehensive sexual and reproductive health care is essential to the quality of life of people living with HIV.

For further information about *Demanding Better*, please scan the following QR code:



ACCESS TO HEALTH CARE

Access to health care remains a vital component of ensuring people living with and vulnerable to HIV can lead healthy, full lives.

- **Secure health care coverage:** Congress must support access to health care coverage, including fixing the Medicaid coverage gap.

For nearly three years, Congress ensured that people enrolled

- in state Medicaid programs did not face interruptions in health care. With Medicaid eligibility redeterminations set to resume on April 1, 2023, millions of people are expected to be disenrolled and become newly uninsured. The impact of this will hit especially hard in states that have chosen not to expand Medicaid eligibility or extend Medicaid continuous postpartum coverage.

- **Address barriers to care:** Congress must remove barriers to health care that people living with or vulnerable to HIV face in the United States, including the chronic underfunding of the Indian Health Service and immigration-related restrictions on who may enroll in Medicaid, Medicare and marketplace coverage.
 - Many people still face difficulty accessing health care. The Indian Health Service faces regular underfunding and uncertain funding, resulting in limited access to care. Additionally, many people living in the United States are routinely barred from or are forced to delay accessing health care coverage (including Medicaid, Medicare and private health insurance sold on the marketplace) due to their immigration status. This keeps necessary medical care, including key preventive care, out of reach for millions of individuals and families.
- **Compassionate and evidence-based care for people who use drugs:** Due to the unstable nature of the illicit drug supply in the United States, syringe services programs and other harm reduction interventions are vital.
 - With the proliferation of fentanyl, fentanyl-related substances and toxic adulterants like xylazine, the potential for fatal overdose and bodily harm for people who use drugs has increased significantly, with more than 110,000 people dying of drug overdose in the United States during a 12-month period from 2021 to 2022. It is essential that people who use drugs are provided with the tools they need to use as safely as possible, and get connected to nonjudgmental, person-focused health care that treats them with dignity and respect.



- If we are going to end the HIV, viral hepatitis and overdose syndemics, the United States must commit to investing in evidence-based harm reduction interventions like the provision of clean syringes and pipes, nonrestrictive medication assisted treatment, widespread naloxone and fentanyl test strip distribution, and infectious disease testing.
- **Protect access to HIV-related drugs: Congress must ensure that people living with or vulnerable to HIV can access HIV-related drugs, including preexposure prophylaxis, or PrEP, which is a medication that prevents HIV.**
 - To end the HIV epidemic in the United States, we must ensure that all people have access to PrEP. This includes ensuring PrEP and related services (e.g., lab testing) are covered with no copay and that people have access to the modality of PrEP best suited for their needs.
- **Treat the whole person: Congress must fund efforts that address the whole person, including social determinants of equity, social determinants of health and health-related social needs.**
 - Health care financing structures must be flexible enough to integrate innovative, effective programming. For example, Congress should authorize and financially support pilot programs that allow hospitals to provide medically tailored meals to people with certain chronic conditions (i.e., the Medically Tailored Home-Delivered Meals Demonstration Pilot Act).
 - Congress must also dedicate resources to address the social determinants of equity, including but not limited to racism, transphobia, homophobia, xenophobia and ableism. Investments in Ending the HIV Epidemic and other initiatives (e.g., combating COVID-19 and mpox) should be community-based, community-led and fully funded.

CIVIL RIGHTS

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 eliminate 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 ongoing and intensified legislative attacks 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 ask that Congress:

- Pass the Equality Act.

Protecting LGBTQ+ youth

A slew of anti-LGBTQ+ legislation has been approved at the state level over the past couple of years. Much of this legislation restricts classroom discussions on sexuality and gender identity and prohibits transgender individuals from fully participating in extracurricular sports. We expect that there will be a significant increase in the number of bills introduced in Congress that mirror those recent state level actions.

LGBTQ+ youth are disproportionately impacted by higher rates of anxiety, depression and suicidal ideation. As a result, our LGBTQ+ youth are especially vulnerable in this mean-spirited and antagonistic climate where elected officials continue to use the very existence of transgender youth as a political wedge issue.

We advocate for all legislation that will support the full dignity and worth of LGBTQ+ youth.

► We ask that Congress:

- Fund the Department of Education in order to provide grants to local school districts around diversity, equity and inclusion trainings.
- Identify the root causes and address the epidemic of violence against transgender and gender nonconforming communities.
- Continue to oppose legislative efforts that would restrict gender affirming care, that restricts LGBTQ+ inclusive curriculum in K-12 schools, or promotes harmful and dangerous tropes about LGBTQ+ people.



Voting rights

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 2023.

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 asking better of our elected officials, we can ensure that voting becomes a fundamental human right.

➤ We ask that Congress:

- Pass the Freedom to Vote Act which includes measures to reform voter registration, integrity and voting access and the John R. Lewis Voting Rights Advancement Act, 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.
- Work with the Department of Justice and each state and territory’s secretary of state on legislation that upholds legally won elections and be proactive with legislation to address states attempting to overturn legally won elections from municipal elections to federal elections.

Gender justice

Women, including transgender 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 transgender 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. In order to ensure adequate gender justice, Congress must also pass legislation to fund programs led by women and transgender people to address housing, the HIV epidemic and other health care needs through a gender equity lens. Also, Congress should pass legislation to require grantees to include intimate partner violence screenings in health care supportive service settings. Additionally, Congress must work with the Biden administration to secure funding for Title X family planning program grantees to maintain affordable access to birth control, screenings for cancer and sexually transmitted infections, and pregnancy testing.



➤ We ask that Congress:

- Pass the Equal Access to Abortion Coverage in Health Insurance (EACH) Act which ensures those who receive health care or health insurance from the government can access abortion coverage.
- Pass the Paycheck Fairness Act to help eliminate the gender wage gap.
- Pass the LGBTQ Data Inclusion Act. 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.

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 ask that Congress:

- Pass the Health Equity and Access under the Law (HEAL) for Immigrant Women and Families Act, which would extend Medicaid and Children’s Health Insurance Program coverage to eligible individuals in the United States.

- Pass the U.S. Citizenship Act, which would expand paths to citizenship for some immigrants and update immigration statutes and processing.

Criminal justice system reform

HIV advocates must be committed to racial justice throughout all aspects of policy, as we know that is the only way we can end the HIV epidemic in the United States. We recognize that the criminal justice system disproportionately burdens the communities most impacted by HIV — people of color and particularly queer and transgender people — and know our advocacy must extend beyond only health policy.

The death of George Floyd in May 2020 was a turning point in the ongoing movement for racial justice and police reform. The George Floyd Justice in Policing Act aims to address systemic issues within the police force and improve accountability and transparency. We were reminded of the urgency of this bill earlier this year when Tyre Nichols lost his life due to the inhumane treatment at the hands of the Memphis Police.

The George Floyd Justice in Policing Act is a crucial step in the ongoing effort to achieve racial justice and reform the police system. We demand Congress to pass this legislation in order to address systemic issues, promote accountability and transparency, and build a more just and equitable society. This is an opportunity for our elected leaders to demonstrate their commitment to ensuring the protection and safety of all Americans, regardless of race.

➤ We ask that Congress:

- Pass the George Floyd Justice in Policing Act.

OLDER ADULTS LIVING WITH HIV

Congress must address the issues related to HIV and aging and address the needs of people living with HIV who are 50 years and older.

People living with HIV who are 50 years and older make up just over 50% of all people living with HIV in the United States. With the success of antiretroviral treatment and adherence, this population will continue to grow in numbers and percentage of all people living with HIV. The Ryan White HIV/AIDS Program projects that by 2030, 64% of Ryan White program clients will be 50 years and older.

While the focus here is on people 50 years and older, the total group of people aging with HIV includes long-term HIV survivors who are under 50 years of age and adults in their 20s and 30s who were born with HIV.

People living with HIV who are 50 years and older face numerous challenges to their health and quality of life. Many of the challenges are common among all people living with HIV and many are common among the general population of older adults. The intersection of HIV and aging, however, creates unique sets of challenges for adults living with HIV. Many of the challenges center around health and health care. The management of comorbidities, issues related to polypharmacy and the quality of health care for older adults are predominant concerns. Far too many older adults living with HIV experience inadequate health care.

Social isolation, loneliness and depression are also common issues among older adults living with HIV. Inadequate levels of, and limited or no access to, mental health programs, programs that address alcohol and substance use disorders, housing, transportation, food and nutrition, and programs to eliminate stigma and discrimination are an unacceptable reality for many people living with HIV who are 50 years and older.

A health care workforce and social services workforce that are not fully competent to address HIV and aging and are not fully competent in cultural sensitivity and humility compounds the challenges faced by people aging with HIV.

The updated National HIV/AIDS Strategy (2022-2025) that was released on World AIDS Day 2021 for the first time has an objective that specifically calls for providing whole-person care for older adults living with HIV and long-term survivors. Congress must work to ensure that all components of the public and private sectors have the policies, resources and programs needed for optimal health and quality of life for people who are aging with HIV.

➤ We ask that Congress:

- Pass legislation that appropriates designated funding to develop new and support existing programs and models of care that provide comprehensive health care for older adults living with HIV that integrate HIV care, chronic disease management, and geriatric assessment and care.
- Reauthorize the Older Americans Act and include language that designates older adults living with HIV as a population “of greatest social need.”
- Pass legislation that ensures that older adults living with HIV are prioritized in public health responses to infectious disease outbreaks and epidemics, such as COVID-19, mpox, respiratory syncytial virus and new viral infections.



— Pass legislation that incentivizes the development and implementation of programs to increase the capacity of health care and social services workforces to address HIV and aging, and increase cultural sensitivity, competency and humility among these workforces.

HIV DECRIMINALIZATION AND MODERNIZATION

HIV criminalization laws contribute to people living with HIV being targeted and punished beyond the courtroom. HIV criminalization laws contribute to the health implications of people living with HIV as 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 penalizing marginalized communities like Black and Latinx gay and bisexual men, cisgender and transgender women, and people who engage in sex work, a population that historically encounters health inequities.

Modernization or repeal of HIV criminalization laws requires states to act. However, 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.

Molecular HIV surveillance

Molecular surveillance refers to technologies that collect personal genetic health care information for public health surveillance and intervention purposes by state, local and national public health officials.



In particular, molecular HIV surveillance uses individual treatment resistance information collected by providers to see how patients would respond to drugs that the provider might prescribe. Providers are then required to report individualized resistance information to health departments, which use the information to map highly detailed networks of HIV transmission in a process CDC references as cluster detection and response.

Any public health strategy for ending the HIV epidemic must be built on a strong foundation of trust. People living with and vulnerable to HIV must be able to interact with the health care system without fear of having their lives or serostatus weaponized against them in the future. In an ideal world, public health researchers would be able to guarantee to the HIV community that their use of molecular HIV surveillance and cluster detection would be entirely ethical and safe, with no possibility of being used to harm them in the criminal system. We do not live in that world. Many states continue to increase meritless penalties against people living with HIV, and these cluster detection systems are not consensually tracking their health data. This causes many people to fear prosecution, which is a deterrent to HIV testing.

If the benefits of molecular HIV surveillance are ever to outweigh the risks, the individual rights and privacy of people living with HIV must be prioritized, and the concerns of the HIV community must be addressed.

➤ We ask that Congress:

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

APPROPRIATIONS

To reach the ambitious — but achievable goal — of ending the domestic HIV epidemic by 2030, Congress will need to join the Biden administration and community efforts by increasing investments in our public health infrastructure and by centering racial justice in our public policy responses to the epidemic. 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 that will enable us to end the epidemic here. Their full recommendations can be seen at bit.ly/HIVFY24.

We ask that Congress fund the following programs at these levels in fiscal year 2024:

- The Ryan White HIV/AIDS Program — \$3.058 billion
- Housing Opportunities for People With AIDS (HOPWA) — \$600 million

- Minority HIV/AIDS Fund — \$105 million
- Ending the Epidemic supplemental funding across programs — various amounts
- Opioid-Related Infectious Diseases program within CDC — \$150 million

We can no longer afford level funding or meager funding increases from year to year. As HIV community-based organizations continue to recover from COVID-19 disruptions in addition to the typical challenges associated with maintaining HIV services in community health centers, we need a significant investment into the HIV safety net in the 2024 budget.



The Ryan White HIV/AIDS Program — \$3.058 billion

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 33 years after its creation. Nearly half the 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 people over 50 representing 47% of Ryan White clients. Nearly three out of four Ryan White clients are racial and ethnic minorities, with 47% of Ryan White clients identified as Black or African American. However, program funding has not increased to match the pace to provide care to all who would benefit — particularly communities who remain disproportionately impacted by new HIV diagnoses.

Housing Opportunities for People With AIDS — \$600 million

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 HIV/AIDS Fund — \$105 million

Twenty-five years ago, the Minority AIDS Initiative was created to provide funding streams to minority-led, community-based organizations that provide HIV care. Communities of color, long impacted by structural racism, must always be centered in federal efforts to end the domestic HIV epidemic. The Minority AIDS Initiative funding promotes collaboration between HHS-funded programs to enhance already existing HIV care. We request that Congress ensure that the original intent of the program is implemented to augment federal spending with complementary programs led by and serving communities of color most impacted by HIV.

Ending the Epidemic supplemental funding across programs

The Ending the HIV Epidemic initiative 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, whole-of-government initiative by further funding the involvement of other critical agencies — namely the Department of Housing and Urban Development, the Substance Abuse and Mental Health Services Agency and the Centers for Medicare and Medicaid Services.

Opioid-Related Infectious Diseases program within CDC — \$150 million

We cannot end the HIV epidemic in the United States without ending 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. They also understand the essential role that syringe services programs play in our efforts to prevent HIV and viral hepatitis transmission. 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.

CLOSING

As we celebrate the 30th Anniversary of AIDSWatch, the largest constituent-led HIV advocacy event in the country, with our planning partners — AIDS United, the US People Living with HIV Caucus and the Center for Health Law and Policy Innovation — we thank you for the action you've taken on the state, local and national level for people living with and vulnerable to HIV. While there has been tremendous progress since that first AIDSWatch, the need for vigorous action on the HIV epidemic is critical, and your attention to your constituents' needs continues to be invaluable.

Whether it's quality of life, access to health care, civil rights, aging with HIV, HIV decriminalization or federal appropriations, we were pleased to share with you several policy priorities that can make a profound impact on the health and well being of people living with HIV on the local, state and national level. Thank you for your help in information sharing and educating. We look forward to continuing to work with you to ensure Congress provides us with the tools necessary to address the needs of people living with and vulnerable to HIV.

For further information about AIDSWatch and our community's priorities, please visit www.aidsunited.org/AIDSWatch, or be in touch with the AIDS United Policy Department at policy@aidsunited.org with questions about these policy recommendations or for further support on HIV policy.



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NOTES

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30 YEARS OF ACCELERATING ACTION

March 2023