



BIG IDEAS

**ENDING THE HIV EPIDEMIC —
SUPPORTING ALL PEOPLE WITH HIV AND REDUCING NEW TRANSMISSIONS**

URGENT ACTION IS NEEDED IN 2021 TO END HIV IN THE UNITED STATES

AS WE MARK THE 40TH ANNIVERSARY of the discovery of the first cases of HIV this June, the United States should celebrate progress on HIV while addressing the challenges that remain. These challenges include large disparities in who is most impacted by HIV, which are rooted in social and structural inequities that create the conditions in which certain groups are especially vulnerable to HIV, including people of color, gay and bisexual men, and transgender people. In 2021, what steps are needed to move the U.S. toward ending HIV in a way that improves equity and supports efforts to recover from the COVID-19 pandemic?

There is no doubt that the COVID-19 pandemic has impeded efforts to fight HIV, but while the pandemic is a setback, it does not make responding to HIV any less critical. Short- and long-term behaviors and patterns have been altered by COVID-19 leading to fewer people starting or maintaining a regimen of pre-exposure prophylaxis (PrEP),¹ fewer HIV tests being performed, HIV clinics and programs closing (both temporarily at the beginning of the COVID-19 pandemic and in some cases permanently), and HIV clinicians and public health officials being diverted to the COVID-19 response.² Nonetheless, the response from the HIV community to COVID-19 also shows the responsiveness and resilience of many HIV institutions. To prioritize policy changes for the next phase of the HIV response, action is needed in four areas:

1. REFINE THE ROADMAP TO ENDING HIV

When the first National HIV/AIDS Strategy was released in 2010, it had a galvanizing impact and represented a new effort to focus on a defined set of common goals. The second iteration, released in 2015, had a similar impact. Building on the original, it was updated to account for the existence of PrEP,

new research showing the effectiveness of early HIV treatment at preventing onward transmission, and insurance coverage expansions brought about by the Affordable Care Act (ACA).³ Similarly, the Ending the HIV Epidemic (EHE) Initiative was launched in 2019 with bipartisan support.⁴ It brought renewed excitement, with its bold vision of actually ending the domestic epidemic (defined as reducing new transmissions by 90% by 2030 from 2019 levels) and its data-driven focus. Phase 1 includes the 48 counties

A FOCUSED AGENDA CAN DRIVE HIV PROGRESS

ENDING HIV REQUIRES STRATEGIC POLICIES AND ADEQUATE FUNDING. KEY ACTIONS IN 2021 ARE:

Refine the Roadmap to Ending HIV

Update the National HIV/AIDS Strategy and bolster the EHE Initiative

Protect HIV Civil and Human Rights

Restrict law enforcement access to public health data and modernize HIV criminal laws

Strengthen HIV Health Care Systems

Expand Medicaid in all states and improve HIV prevention and care for Medicaid beneficiaries

Respond to the neglected needs of people aging with HIV

Build Stronger and More Resilient Communities

Support HOPWA and address housing affordability

where most HIV transmissions occur, along with Washington, DC, San Juan, Puerto Rico, and seven rural states with large HIV populations and more limited health systems.

Critically, the EHE Initiative has delivered new discretionary resources to fight HIV, focused more intently on the places and people most heavily impacted by HIV, and accelerated the adoption of the most effective strategies for preventing and treating HIV, including extending the messaging that U=U (undetectable equals untransmittable) thereby creating a new dialogue about the importance of adherence to treatment to maintain durable viral suppression.⁵ In addition, the EHE Initiative has brought other innovations, including the America's HIV Epidemic Analysis Dashboard (AHEAD) that provides the public and policymakers with new data visualizations to track progress.⁶

POLICY ACTION: UPDATE THE NATIONAL HIV/AIDS STRATEGY AND BOLSTER THE EHE INITIATIVE.

Prior to assuming office, President Biden pledged to release a new National HIV/AIDS Strategy.⁷ This is an important opportunity for mobilizing commitment and action for the next phase of progress. In January 2021, the Trump Administration published its HIV National Strategic Plan.⁸ This was developed following community consultation and should serve as a starting point for the next update to the National HIV/AIDS Strategy; this will ensure that there is a single unified national approach that does not delay movement from planning to implementation. Through the EHE Initiative, the last Administration supported efforts to focus on the populations at greatest risk for HIV, launched a new program to expand access to PrEP, and worked to get people with HIV into care and on treatment as soon as possible. It did not, however, support other key HIV priorities such as bolstering the ACA and protecting the civil and human rights of transgender people and other LGBTQ+ people. It also refused to acknowledge many of the structural barriers leading to inequitable HIV outcomes.

This Administration can do more. In an encouraging sign, in April 2021, the Biden Administration signaled its commitment to the EHE, stating that it will request \$670 million for the Initiative in its FY 2022 budget request.⁹ It also has begun taking steps to enforce non-discrimination protections in health care on the basis of gender identity and sexual orientation.¹⁰ It should identify further actions in the Strategy to protect civil and human rights and address racism and structural barriers to equitable health outcomes, which are part of its broader commitment to racial justice and health equity. As the Administration updates the Strategy, it would be strengthened by more explicit commitments to community engagement in setting goals and monitoring progress and a more intentional

focus on improving the quality of life of people with HIV beyond viral suppression as the only metric. It should seek to build upon the EHE and extend elements of the Initiative to lower prevalence parts of the country, even as it continues to concentrate attention on the places and populations most heavily impacted by HIV. The Strategy should align with and support broader efforts to rebuild the nation's public health workforce that has lost about 20% of state and local public health jobs since 2008, and should address the HIV clinical care workforce, including the need for a robust pipeline for infectious disease specialists.¹¹ In an analysis published in 2020 before being appointed to her role, Centers for Disease Control and Prevention (CDC) Director Rochelle Walensky and colleagues reported that 80% of U.S. counties do not have a single infectious disease physician.¹² The Strategy also can leverage recent initiatives, including funding in the American Rescue Plan, enacted in March 2021, to bolster the workforce and modernize data systems.¹³ Doing so would be transformative in helping to enhance existing HIV surveillance and monitoring systems to work more seamlessly and effectively across various data sets and to use new technologies to provide more timely information to respond to COVID-19, HIV, viral hepatitis, sexually transmitted infections (STIs), and substance use disorder epidemics.

2. PROTECT HIV CIVIL AND HUMAN RIGHTS

Widespread stigma and discrimination faced by people with HIV and communities with a heavy burden from HIV have been major issues since the beginning of the epidemic and remain deeply problematic today. HIV is often stigmatized because it is associated with sexual and drug-using behaviors. As the country faces a crisis of overdose deaths and growing rates of substance use disorders, stigmatization of people who use drugs has led to indifference and even opposition to public health responses. As a result, drug use is often criminalized, creating a well-worn pathway to incarceration that imposes costs on society and in some places directly impedes the delivery of evidence-based prevention and care services, such as overdose prevention services, syringe services programs (SSPs), and medication-based treatment for opioid use disorder and other substance use disorders. To facilitate greater SSP capacity, Congress should eliminate the prohibition on the use of federal funds for the purchase of syringes when used as part of an SSP. Relevant federal agencies should place greater emphasis on working with states and local jurisdictions to adopt evidence-based substance use disorder prevention and treatment programs and eliminate barriers such as state paraphernalia laws. A broader set of reforms also are needed to change sentencing practices for drug offenses, expand pre-arrest diversion programs, and remove eligibility

CRIMINAL LAWS AND PRACTICES MUST ALIGN WITH SCIENCE AND PUBLIC HEALTH

SCIENCE SHOWS HOW TO STOP HIV TRANSMISSION

U=U

Research has proven that undetectable equals untransmittable, meaning that persons with HIV who are durably virally suppressed cannot pass HIV to their sexual partners.

Prevention

Condoms, PrEP, PEP syringe services programs, and other risk reduction strategies empower individuals to protect themselves from acquiring HIV.

Problematic Laws and Policies Persist

The Federal Government, 32 States, and 2 Territories have HIV-specific criminal laws and/or sentence enhancements applicable to people with HIV.

Over 400 cases of arrest and prosecution for HIV exposure have been documented from 2008-2019.

SOURCE: Center for HIV Law and Policy.

restrictions for other public services, such as federal housing assistance for persons with drug-related convictions.

Stigma and discrimination related to HIV and drug use are connected to entrenched racism, homophobia, transphobia, economic disadvantage, mass incarceration, geographic segregation, and other factors. With increasing recognition of the need to finally tackle social inequities that impact health outcomes, it is important to support systemic approaches to social change, such as the Movement for Black Lives, efforts to counter anti-Asian hate, advocacy for immigrant rights, and the push for criminal justice reforms. Working intersectionally and advocating for civil and human rights must be a core part of the HIV community's agenda.

POLICY ACTION: RESTRICT LAW ENFORCEMENT ACCESS TO PUBLIC HEALTH DATA AND MODERNIZE HIV CRIMINAL LAWS.

A specific policy issue with special salience to people with HIV relates to laws and practices that criminalize HIV non-disclosure, exposure, or transmission.

Enhancing collective efforts to modernize such laws and change policies and practices is critical to ending the HIV epidemic. When the Ryan White CARE Act was enacted in 1990, Congress required states to certify that their criminal laws could prosecute individuals for knowingly exposing another person to the virus.¹⁴ This led to the proliferation of state laws that are still being used to this day to prosecute individuals, typically for failure to disclose their HIV status before having sex (or for behaviors that have negligible risk for transmission). Such laws do not reflect the science of HIV transmission and disproportionately fall on low-income people of color.¹⁵ The pervasive risk of HIV criminal prosecutions creates community concerns around implementing a public health strategy called molecular surveillance as part of HIV cluster detection. HIV molecular surveillance involves analyzing differences in the genetic sequence of HIV viruses circulating within a community to identify places and communities where HIV is spreading rapidly.¹⁶ This tool is an integral part of the EHE Initiative and has been able to identify unknown clusters of transmission enabling more timely and comprehensive public health responses.¹⁷ The same technology also is being used to identify new variants of the COVID-19 virus and document potential cases of re-infection. Some HIV community stakeholders strongly oppose the use of this tool, however, because of its potential misuse in the criminal prosecution of people living with HIV.

Despite the HIV community advocating at the state level to modernize HIV criminal laws and making progress in some states,¹⁸ the pace of modernization is too slow. While the Ryan White CARE Act certification requirement no longer exists, federal policy can do more to stop the ongoing harm that its prior policies helped to establish. CDC awards roughly half of its HIV prevention funding to state and local health departments through five-year cycles that establish priorities and funding requirements. CDC could use the next funding announcement that will run from 2023-2028 to establish new data protection requirements. This could include, for example, new steps to limit law enforcement access to public health surveillance data by prohibiting the use of CDC funds for staff time, equipment, or technology to conduct molecular surveillance analyses unless there is a law or policy to prohibit disclosures of molecular surveillance data to law enforcement. While CDC policy cannot control all state actions, federal policy should seek to prevent charging and prosecuting people with HIV in connection with their HIV status, except in rare instances of willful and intentional transmission.

3. STRENGTHEN HIV HEALTH CARE SYSTEMS

Prior to the ACA, people with HIV were roughly 50% more likely to be uninsured than the general

SIGNS OF PROGRESS

HIV Viral Suppression Increased among all people with HIV in the U.S. from 28% in 2010 to 56% in 2018.

New HIV Diagnoses Decreased by 11.4% from 2010 to 2018.

People with HIV Are Just as Likely to be Insured as the general population. Prior to the ACA, people with HIV were much more likely to be uninsured.

MORE ATTENTION NEEDED

Declining Diagnoses Have Stalled since 2018.

Resurgence of HIV Cases Among People Who Use Drugs. Diagnoses among people who inject drugs increased 9% from 2014 to 2018.

COVID-19 Pandemic Creates Stress on communities and the HIV services system.

SOURCE: HIV National Strategic Plan, 2021-2025; Insurance Coverage and Viral Suppression Among People with HIV, 2018, Kaiser Family Foundation, September 2020; *Vital Signs: and HIV and Injection Drug Use*, CDC (Nov. 29, 2016) and *HIV: HIV in the United States and Dependent Areas*, CDC (Nov. 24, 2020).

population.^{19,20} A Kaiser Family Foundation analysis, however, found that due to ACA coverage expansions, people with HIV were no more likely to be uninsured in 2018 than the population as a whole.²¹ Despite this progress, an amfAR analysis found that people with HIV in the EHE focus counties were 17% more likely to be uninsured than people with HIV in the nation as a whole.²² While ACA marketplace coverage is important, the most significant increases in insurance coverage for people with HIV have come from Medicaid expansion. Unfortunately, 12 states—including high population states such as Florida, Georgia, North Carolina, and Texas—have not expanded Medicaid.²³

POLICY ACTION: EXPAND MEDICAID IN ALL STATES AND IMPROVE HIV PREVENTION AND CARE FOR MEDICAID BENEFICIARIES.

The most impactful way to continue improving HIV health outcomes and expand access to HIV prevention services is for all states to expand Medicaid. The American Rescue Plan includes

incentives to encourage states to take up this option, but more work is needed to overcome state-level opposition and to support states with large HIV populations that have poorly performing Medicaid programs. Medicaid's cost-sharing protections are far stronger than private coverage, and the networks of primary care providers, including federally qualified health centers, are often better equipped to competently serve low-income populations. Even so, federal leadership can take steps to strengthen Medicaid. For example, the Centers for Medicare and Medicaid Services (CMS) could enhance beneficiary protections (including ensuring that all beneficiaries with HIV have access to all recommended regimens in the DHHS HIV treatment guidelines), tighten actuarial soundness requirements that ensure that managed care organizations are adequately funded to meet their coverage obligations, and establish benchmarks for reasonable reimbursement rates in the fee-for-service system. CMS also could tighten requirements for network adequacy, including for specialty care. Further, to identify and respond to inequitable outcomes and improve equity, CMS leadership is needed to strengthen monitoring and reporting on people living with and at-risk for HIV, stratified by gender, risk group, and race/ethnicity. This should include services use (including PrEP, HIV treatment, mental health and substance use disorder services, etc.), satisfaction, and outcomes along the HIV care continuum.

POLICY ACTION: RESPOND TO THE NEGLECTED NEEDS OF PEOPLE AGING WITH HIV.

It has been projected that by 2030, 70% of people with HIV in the U.S. will be age 50 or over.²⁴ This group requires more attention to understand clinical manifestations of HIV and its interaction with the aging process, as well as to meet their health care, social services, and emotional needs. Despite being a large part of the HIV community, their specific needs are often overlooked. HIV programs and services often need a more intentional focus on being more responsive to people who are aging with HIV. While current programs deliver services that can support people with HIV who are aging, threats to comprehensive drug coverage in the Medicare Part D program illustrate vulnerabilities that could erode current protections. Further, longitudinal research is needed to better understand the long-term impact of HIV infection, as well as the long-term effects of older and newer forms of HIV treatment. More energy is also needed to thoughtfully integrate HIV programs and services with the broader network of aging programs and services.

ADOPTING A NEW VISION FOR THE NEXT DECADE OF FIGHTING HIV

THE HIV COMMUNITY NEEDS A NEW ANIMATING VISION FOR THE NEXT DECADE OF THE HIV RESPONSE. POTENTIAL GOALS ARE TO:

INVEST IN IMPROVING QUALITY OF LIFE

It is time to expand our view of success. Durable viral suppression remains essential, but it must exist alongside targets for helping to prevent and manage other health threats and tackle social and structural barriers to a high quality of life. Even as our current HIV safety net covers many of the health care basics, too many people with HIV are financially insecure, face social isolation, and feel that they are being left behind. We need expanded metrics to track progress.

16YRS

A STUDY OF CO-MORBID CONDITIONS SUCH AS CANCER AND CARDIOVASCULAR DISEASE FOUND THAT PEOPLE WITH HIV EXPERIENCED THEIR FIRST CO-MORBIDITY 16 YEARS EARLIER THAN HIV-NEGATIVE PEOPLE.²⁵

48%

BLACK AND LATINX GAY AND BISEXUAL MEN MADE UP ABOUT 48% OF HIV DIAGNOSES IN 2018 EVEN THOUGH THEY COMPRISE ONLY ABOUT 1% OF THE POPULATION.²⁶

EMBRACE BLACK AND LATINX GAY AND BISEXUAL MEN AND TRANSGENDER PEOPLE AND OFFER A VISION FOR THEIR SEXUAL HEALTH

Black and Latinx gay and bisexual men acquire HIV at a younger age than other groups, and transgender people, especially transgender women, are also extremely vulnerable to HIV. We need a new vision for sexual health and healthy development that better enables parents, families, and society to protect them from HIV by embracing their identity and the LGBTQ+ community while teaching about healthy relationships and the importance of the full range of prevention tools from condoms to PrEP. For those living with HIV, there is a need for more culturally grounded approaches to support engagement in care and adherence to treatment.

EXPAND THE CAPACITY OF THE RYAN WHITE HIV/AIDS PROGRAM TO GET MORE PEOPLE WITH HIV INTO CARE

Funding for the Ryan White HIV/AIDS Program in FY 2021 is \$87.1 million higher than in FY 2011, although reduced when accounting for inflation. Current funding, along with insurance coverage, has helped achieve viral suppression rates on par with other high-income countries and has helped to reduce HIV-related disparities. Nonetheless, more funding is needed to expand the capacity of the program to reach the estimated 23% of people with HIV who were diagnosed, but not in care in 2016. 43% of new transmissions originate from this group. (d)

88%

88% OF PEOPLE RECEIVING RYAN WHITE SERVICES WERE VIRALLY SUPPRESSED IN 2019. FOR THE NATION AS A WHOLE, SLIGHTLY MORE THAN HALF (56%) WERE IN 2018.^{26,27}

↓21%

AFTER ADJUSTING FOR INFLATION, THE HIV RESEARCH BUDGET AT THE NATIONAL INSTITUTES OF HEALTH (NIH) IN FY 2021 IS DOWN 21% COMPARED TO FY 2011.²⁹

DEVELOP AND DEPLOY VACCINES FOR HIV PREVENTION AND A FUNCTIONAL CURE FOR HIV BY 2030

NIH has invested steadily in HIV vaccine research, and while progress is being made, it is too slow. Let's take inspiration from the rapid progress at developing a COVID-19 vaccine and show the same determination and funding commitment to accelerate HIV vaccine development and research, specifically into broadly neutralizing antibodies (bnAbs) that are yielding promising results and could produce transformative advancements, both for HIV prevention and treatment.

SCALE-UP ACCESS TO EFFECTIVE PREVENTION AND SUBSTANCE USE DISORDER SERVICES

CDC HIV prevention funding in FY 2021 was up 3% compared to FY 2011 after adjusting for inflation, yet it was still only 13% of the federal discretionary HIV budget. There are many effective, evidence-based interventions, overdose prevention services, and other harm reduction services. However, too often, funding is too low to ensure widespread access to achieve population-level declines in HIV transmissions.³³

18.2%

IN 2018, ONLY 18.2% OF PEOPLE WITH A PREP INDICATION WERE RECEIVING IT, AND IN 2016, ONLY 11% OF PEOPLE WITH AN OPIOID USE DISORDER WERE RECEIVING MEDICATION-BASED TREATMENT.^{30,31,32}

CDC estimates that during 2008-2017, about 10,000 fewer new HIV transmissions occurred each year as compared to years prior, preventing more than 100,000 HIV cases over the decade, and saving \$4.58 billion. But this is not enough. **Expanded investments and a bolder vision are needed to meet the EHE goals.**

4. BUILD STRONGER AND MORE RESILIENT COMMUNITIES

Ending the HIV epidemic depends on healthy and resilient communities, and there is a growing recognition that social determinants underlie many health inequities, challenging policymakers to think outside of health programs to improve health. This includes everything from ensuring that people feel

physically safe in their communities to expanding employment opportunities and access to high-quality jobs. One challenge that is deeply felt by many people living with HIV is housing stability, the need for which has been spotlighted by the COVID-19 crisis.

POLICY ACTION: SUPPORT HOPWA AND ADDRESS HOUSING AFFORDABILITY.

Numerous studies have shown that improving housing status has an independent effect on improving HIV outcomes and that people who are homeless or have other housing needs are less likely to be engaged in care at all stages of the HIV care continuum compared to counterparts without housing challenges.³⁴

In 2016, Congress modernized the Housing Opportunities for People with AIDS (HOPWA) Program that changed the funding structure to award funding based on living HIV/AIDS cases in a jurisdiction. Subsequently, Congress increased funding for the program to ensure that people with HIV would not lose HOPWA assistance as this funding method was implemented. In FY 2021, \$430 million was appropriated for HOPWA (one-time funding of \$65 million also was appropriated in 2020 for COVID-19 relief).³⁵ The program provides housing stability for roughly 55,000 households of people with HIV each year.³⁶ FY 2022 is the first year that the new formula will be fully in effect, and the HIV community is requesting HOPWA funding of \$600 million.³⁷ The U.S. has a larger crisis of access and affordability of housing. Strengthening housing affordability and stability more broadly so that people living with and at risk for HIV have multiple avenues to access housing assistance will enable the HOPWA program to use its resources differently and deliver even larger improvements in HIV outcomes. In 2021, the Biden Administration proposed significant investments to tackle housing affordability³⁸ that, along with increased HOPWA funding, could support the next wave of progress toward meeting the nation's ending the HIV epidemic goals.

THE TIME IS NOW

As the U.S. marks four decades of responding to one of the most consequential global health threats in our lifetimes, let's use the momentum of the past to propel renewed and enhanced commitment to action. If the federal government, state and local governments, and community stakeholders take the right steps today, we can move even closer to ending the HIV epidemic over the next decade.

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