



BIG IDEAS

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

IMPROVING THE QUALITY OF LIFE OF PEOPLE LIVING WITH HIV MUST GUIDE THE IMPLEMENTATION OF THE NATIONAL HIV/AIDS STRATEGY

THE HIV EPIDEMIC IN THE UNITED STATES REMAINS A SERIOUS HEALTH CRISIS.

Determined efforts over the past four decades, however, have produced major advances, including a large and growing array of effective treatments and prevention modalities. Nonetheless, these achievements obscure a reality that many people living with HIV are not doing well. Only about two-thirds of people living with HIV achieve and maintain HIV viral suppression, co-morbid conditions continue to threaten their health, and other aspects of people's lives remain challenging.^{1,2} Therefore, there is a need to adopt a more holistic vision of success. In December 2021, President Biden released the latest *National HIV/AIDS Strategy for the United States*, which identifies priority actions for 2022-2025.³ More than ever before, it focuses on improving quality of life. Sustaining this focus must be the guiding light for our collective efforts to achieve the Strategy's vision.

WHAT IS NEEDED TO BETTER SUPPORT PEOPLE LIVING WITH HIV?

It is possible to think that the U.S. simply needs to maintain current efforts to eliminate HIV as a public health threat. Sustaining current efforts, however, is insufficient, and the nation needs to plan to increase investments in health care and social supports for 1.2 million people living with HIV while funding prevention services for growing numbers of people who remain vulnerable to acquiring HIV. While stories of success abound where people living with HIV lead excellent lives and HIV is a manageable part of life, this is not the reality for too many people who often

ACHIEVING A MORE HOLISTIC HIV RESPONSE

Success in meeting the needs of people living with HIV includes, but is not limited to, supporting viral suppression. Urgent action is needed to:

Update Social Security Programs and address employment needs to increase financial security

Elevate interventions to address stigma and social isolation in the Ryan White HIV/AIDS Program

Develop new clinical guidelines on whole person health for people living with HIV

Develop a policy and research agenda that more intently focuses on understanding, measuring, and improving quality of life

face fear, insecurity, stigma, trauma, and consequently, an array of complex health and social challenges. Therefore, there is a need for a broader perspective that prioritizes long-term health, especially as people live longer and age with HIV. This also includes tackling laws and policies that criminalize people with HIV and combatting systemic racism, which is increasingly recognized as a public health issue and continues to fuel the large disparities in terms of which communities are most heavily impacted by HIV. Further, inadequate access to safe and

affordable housing and the absence of employment opportunities that pay a living wage are among the structural barriers to a high quality of life.

One of the biggest challenges to ending the HIV epidemic is that too frequently people living with HIV are trapped in poverty. Our country's main way of providing income support is through the Social Security disability programs (see text box on the next page). An estimated half of adults in the U.S. with HIV receive federal disability benefits.⁴ Payment levels for these programs, however, leave people near or below the federal poverty level. Further, restrictive state income eligibility rules for essential programs such as Medicaid and AIDS Drug Assistance Programs (ADAPs) sometimes force people to choose between working and receiving essential services.

POLICY ACTION: Update Social Security Programs and address employment needs to increase financial security.

The federal commitment through the Supplemental Security Income (SSI) Program to people with serious and permanent disabilities without a qualifying work history only ensures financial support at less than three-fourths of the federal poverty level (FPL). There is an urgent need to re-examine and increase support levels. Given the concern with the federal deficit and looming shortfalls in the trust fund that finances the Social Security Disability Insurance (SSDI) Program, some may perceive recalibrating SSI payment and SSDI benefit levels as politically unachievable. Other policy advances, however, including expanding Medicaid to people with incomes up to 138% of FPL and making the child tax credit refundable and more generous, seemed unachievable before they were enacted. Such advances came about only after years of effort. In a similar vein, the HIV community should partner with other groups to advocate to increase SSI payment and SSDI benefit levels to support a basic standard of living even if this requires a multi-year commitment. Individuals receiving disability benefits can earn up to \$1,310 per month, the federally determined level of substantial gainful activity (SGA).⁵ Due to a historic relic, SGA for persons who are blind is higher than for other people with disabilities, at \$2,190/month. As an interim step, advocates could call for increasing SGA for non-blind people with disabilities to the same level.

While not all people living with HIV are able to work, a promising way to increase financial security is to expand knowledge of and access to existing work incentive programs as well as to allow people to work and earn more income without losing disability benefits. Too few people living with HIV are accessing these programs frequently because they are unaware of them and misunderstand the complex rules that could threaten their disability benefits.⁶ The HIV/

AIDS Bureau (HAB) at the Health Resources and Services Administration (HRSA), which administers the Ryan White HIV/AIDS Program, can assist with this issue by acknowledging and promoting to its grantees that employment services are an allowable non-medical case management service as a means of improving medical outcomes. This should be one component of a broader effort to work with grantees to develop model employment services initiatives and increase awareness of various programs in order to increase the capacity of case managers to understand and help clients navigate the intricacies of these programs. HIV advocates also should engage with and support broader efforts to improve and expand programs that allow individuals with disabilities to increase income and asset limits for benefits eligibility. A number of groups, such as the Bipartisan Policy Center, have offered proposals to streamline and simplify Medicaid Buy-In Programs for people with disabilities,⁷ and to improve SSDI's work incentives while also strengthening its financing.⁸

POLICY ACTION: Elevate interventions to address stigma and social isolation in the Ryan White HIV/AIDS Program.

People living with HIV often face intersectional stigma (i.e. multiple, overlapping stigmatized aspects of a person's life), discrimination, and social isolation. This can lead to chronic depression and other negative health outcomes. It is critical to address the ways homophobia, transphobia, racism, xenophobia, ageism, and HIV stigma intersect to impact quality of life. All of these forms of discrimination compound to generate barriers to programs, services, and life opportunities. We have previously offered policy recommendations to address intersectional stigma, discrimination, and social isolation in the context of supporting people who are aging with HIV.⁹ These types of efforts are critically important for people of all ages living with HIV. With respect to social isolation, federal HIV programs can do more to facilitate social connectedness. The Ryan White HIV/AIDS Program, in particular, has historically supported a number of services and initiatives to increase social engagement and should consider ways to communicate the permissibility and benefits of such interventions in its guidance and dialogue with grantees over how Ryan White HIV/AIDS Program funds can be used. Recognizing the centrality of social engagement and community connectedness and identifying priority services for increasing social engagement and community connectedness would be a step forward.

LIMITED INCOMES AND HIGH HOUSING COSTS TRAP PEOPLE WITH HIV IN POVERTY

The federal government operates two main income support programs for people under age 65 who have disabilities. Administered by the Social Security Administration (SSA), both of these programs, Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) require individuals to be determined to have a disability that makes them unable to be gainfully employed in the national economy due to a significant medically-determinable impairment that is expected to last for at least 12 months or result in death. For people with HIV, this effectively requires individuals to have advanced disease (previously considered an AIDS diagnosis). In cases that involve medical evidence of a substance use disorder or alcoholism, SSA must determine that this is not a 'contributing factor material to the determination of disability,' essentially meaning that the person still would meet the criteria for a disability even if they stopped using drugs or alcohol.

Social Security Disability Insurance (SSDI) provides a monthly benefit tied to prior earnings. People who earned higher wages when they were working receive a higher monthly benefit. In 2021, the average monthly SSDI payment for a non-blind person with a disability under age 65 was \$1,294 per month or 120% of the federal poverty level.² After receiving SSDI for 29 months from a disability determination, individuals become eligible for Medicare.

Supplemental Security Income (SSI) provides a monthly payment that is 74% of the federal

poverty level. In 2022, the SSI payment for a single individual is \$841 per month and \$1,261 for a couple.³ Some states provide a small supplemental benefit to account for higher living costs, but these state supplemental payments account for less than 4% of SSI payments for persons who are blind or have disabilities.⁴ Persons receiving SSI are generally eligible for Medicaid. Eight states, called 209(b) states, are permitted to have different financial and/or functional eligibility standards for Medicaid.⁵ Individuals can receive both SSDI and SSI. When the SSDI benefit is below the monthly SSI payment level, beneficiaries can receive a supplemental payment up to the SSI payment level. An estimated 80% of people with HIV applying for SSDI and SSI in 2007 received SSI alone or SSDI and SSI.⁶ Since about half of all people with HIV receive disability benefits and most people receiving benefits receive SSI, a large portion of people with HIV in the U.S. subsist on income well below the poverty level to meet all of their living expenses, including food, rent, medical cost-sharing and uncompensated medical expenses, as well as any entertainment or other needs.

Disability Payments are Too Low for Basic Housing Costs:

To show how the math does not work, it is instructive to look at SSI payments in light of local housing costs. Nowhere is SSI adequate to cover rent for a one bedroom or an efficiency apartment along with other living expenses.

| | Monthly SSI Benefit in 2021 | % of Median Income | % of SSI for 1-Bedroom Apt | % of SSI for Efficiency Apt |
|-------------------|-----------------------------|--------------------|----------------------------|-----------------------------|
| New York City | \$881 | 13.3% | 204% | 200% |
| Jackson, MS | \$794 | 20.9% | 100% | 94% |
| San Francisco, CA | \$955 | 9.4% | 306% | 246% |

The Department of Housing and Urban Development operates a variety of programs to support affordable housing, including the Section 8 Program and the critically important Housing Opportunities for People with AIDS (HOPWA)

Program. All of these programs, however, are stretched too thin, leaving many vulnerable individuals and families without assistance. HOPWA, for example, is only able to support about 58,000 households of people living with HIV.⁷

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HOW DO WE STRENGTHEN CLINICAL OUTCOMES IN ADDITION TO VIRAL SUPPRESSION?

It is a major achievement that HIV can be transformed into a manageable chronic condition when people have access to the care and receive the support that they need. Indeed, the steady investment in HIV research has led to the development of a broad and growing array of therapeutics (and prevention modalities) that are safe, highly effective, have fewer side-effects, and minimize the emergence of HIV drug resistance. Moreover, innovative, long-acting options are becoming available that offer even more simplicity and flexibility for users. A current challenge, however, is that durable viral suppression (when individuals not only achieve HIV viral suppression, but are also able to consistently maintain this over time) is too low in all groups. A 2020 analysis of adults and adolescents in care in 2016 found that durable suppression was below 50% with significant disparities in terms of demographic characteristics such as race/ethnicity and age. This is consistent with previous studies that have found that Black individuals aged 13–24 years had the lowest prevalence of sustained viral suppression across all demographic groups.¹¹ An analysis by the Centers for Disease Control and Prevention (CDC) of people with HIV at six U.S. HIV clinics found that 62% of patients achieved durable viral suppression, but it took 174 days for half of patients to reach initial suppression.¹² These statistics highlight that not all people with HIV have access to high-quality health care and that clinical and other factors are impeding the ability of many people to achieve this treatment goal.

Another challenge is reorienting clinical care for people living with HIV to address health outcomes beyond viral suppression. Many people living with HIV suffer from multiple physical and mental health comorbidities and have an earlier onset of comorbidities associated with aging, such as cardiovascular disease, liver disease, diabetes, certain cancers, and neurocognitive disorders. People living with HIV who are aged 50 and older are more likely than their peers without HIV to experience comorbidities, and they face different medical and psychosocial issues than their younger counterparts. More intentional focus on responding to the clinical needs of people living with HIV across the lifespan is needed.

POLICY ACTION: Develop new clinical guidelines on whole person health for people living with HIV.

There is a need to prioritize integrated trauma-informed, gender-affirming, and culturally-relevant whole person care in the clinical management of

TO IMPROVE QUALITY OF LIFE, LISTEN TO PEOPLE LIVING WITH HIV

To ensure that programs are effective and uphold human and civil rights for people living with HIV, it is necessary that people with HIV are centrally involved in the development, implementation, monitoring, and evaluation of policies, programs, and services, especially people from communities most directly impacted (such as Black, Latinx, or Indigenous people, low-income individuals, gay and bisexual men, transgender people, and others). People living with HIV also should be fairly and equitably compensated for this labor.

Recommit to the GIPA Principle: GIPA stands for the Greater Involvement of People Living with HIV. This principle has been endorsed by roughly 200 nations around the world. As U.S. HIV programs have sometimes moved away from community-based organizations and become more deeply embedded in mainstream health systems, the culture of and commitment to involving people with HIV in policy development and program implementation have weakened.

Require Community-Led Monitoring of Programs and Services: While formalized metrics such as number of clients served and the percentage of clients who are virally suppressed are important, they miss important indicators of quality. Health care providers and community-based organizations should be required to invest in community-led monitoring to help identify successes, as well as gaps in services.

Ensure Health Settings Are Stigma-Free: HIV advocates changed the world by demanding that programs and services provide welcoming services to all communities. The Ryan White HIV/AIDS Program, for example, has long supported cultural humility trainings and other interventions to ensure that people with HIV are treated with respect and dignity. All too frequently, however, people living with HIV experience bias and discrimination when seeking to access necessary services.

Ensure that Trauma-Informed Care Is Standard Practice: Many people living with HIV have extensive histories of trauma and have experienced and continue to experience discrimination, threats of violence, and financial, housing, and food insecurity. These experiences impact where, when, and how they access health care and other services. An important intervention has been the development of trainings for health care and community-based organization staff to recognize that client behavior often reflects past or ongoing trauma. Building trauma awareness can help to create more welcoming and affirming environments and improve quality of care.

THE RYAN WHITE HIV/AIDS PROGRAM NEEDS MORE TO DO MORE

A critical action of all HIV community stakeholders should be to seek more funding to sustain and expand access to essential services. In many respects, the Ryan White HIV/AIDS Program is the bright spot of the HIV response. Much of the leadership of the Ryan White HIV/AIDS Program, its grantees, and providers understand and support the changes needed to adopt a more holistic approach. Funding, however, has not kept pace with need. **Even with recent funding increases for priority jurisdictions for the Ending the HIV Epidemic (EHE) Initiative, funding for the Ryan White HIV/AIDS Programs in FY 2021 is only 2.4% higher than a decade earlier (FY 2012) and is effectively lower when considering medical inflation.**

The Program has produced impressive results with the resources provided. As just one measure of success, the Program reported in 2020 that 89.4% of clients were virally suppressed, far higher than the national average of all people living with HIV (see HRSA HIV/AIDS Bureau, Ryan White HIV/AIDS Program Client-Level Services Report 2020). More resources are needed to do more to respond to non-HIV-related preventable illness and to support the more holistic approaches that are needed to improve quality of life.

HIV. While different in scope and purpose, this brief is consistent with many of the recommendations in *Demanding Better: An HIV Federal Policy Agenda by People Living with HIV* released by the US People Living with HIV Caucus in July 2021.¹³ In particular, it mirrors their call for a holistic approach and their agenda emphasizing the importance of non-stigmatizing and high-quality sexual and reproductive health care for people with HIV and expanded access to trauma-informed care and services. While few HIV providers would describe their approach to patient care simply as delivering antiretroviral therapy (ART) and measuring viral suppression, when we train providers on high-quality care and measure successful outcomes, the focus on viral suppression can obscure other health and wellness challenges. The Department of Health and Human Services (HHS) publishes the gold standard of clinical guidelines for HIV treating providers.¹⁴ This is made up of seven sets of guidelines including those for ART for adults and adolescents, separate guidelines for opportunistic infections, and corresponding guidelines for pediatrics. Quality of life should be understood as something that includes not only physical health issues such as cardiovascular

disease and diabetes, but also encompasses mental health and sexual and reproductive health, and acknowledges the need for mental health and substance use disorder services among people with HIV who are often undertreated. HHS should consider establishing a new set of clinical guidelines on whole person health for people living with HIV. This would be consistent with the National HIV/AIDS Strategy, which commits the federal government to developing a new Quality of Life indicator to assess and monitor improvements in quality of life for people living with HIV. Importantly, by recognizing the social and structural drivers of HIV and its connections to poverty, such guidelines should emphasize the importance of person-centered clinical care and lead to the development of accountability standards to improve the quality and comprehensiveness of care. Further, HRSA's HIV/AIDS Bureau, working with other partners within HHS, should develop a strategy to ensure the widespread dissemination and use of the guidelines in clinical practice.

WHAT POLICY CHANGES ARE NEEDED TO IMPROVE QUALITY OF LIFE?

The HIV epidemic in the U.S. and our response always have been plagued by systemic racism, homophobia, transphobia, and other forms of interlocking stigma and discrimination. Therefore, our investments in biomedical research and health care services should be driven by a new prioritization around social and structural drivers of good health.

POLICY ACTION: Develop a policy and research agenda that more intently focuses on understanding, measuring, and improving quality of life.

Further action is needed to study, monitor, and implement programs addressing the quality of life of people living with HIV. The Office of AIDS Research (OAR) at the National Institutes of Health (NIH) should conduct listening sessions that bring together people living with HIV and biomedical and social science researchers to identify the most pressing questions concerning quality of life and then adapt the NIH Strategic Plan for HIV and HIV-Related Research: FY 2021-2025¹⁵ to more fully articulate improving quality of life as a primary goal. Elements of quality of life such as addressing "social-structural factors influencing inequalities in HIV testing, engagement and persistence" are broadly referenced in the Strategic Plan, but a clearer articulation of how the success of this plan will lead to improving overall quality of life could help to focus priorities. Further, as the HIV population ages, critical questions related

UNADDRESSED TRAUMA LEADS TO PREVENTABLE ILLNESS AND DEATH

Unaddressed trauma plays a key role in driving morbidity and mortality among people living with HIV. A person who receives antiretroviral therapy (ART) soon after an HIV diagnosis and who achieves and maintains viral suppression can live a nearly typical lifespan. On average, however, people with HIV live approximately nine years fewer than people who do not have HIV.¹ This disparity in life expectancy is even greater for women with HIV, who live, on average, 12.1 years less than women without HIV.² Furthermore, compared to people who do not have HIV, people living with HIV experience 16.3 fewer years free of major chronic comorbidities, including chronic liver disease, chronic kidney disease, chronic lung disease, diabetes, cancer, and cardiovascular disease.³ A primary cause of these shorter lives has been attributed to non-HIV-related preventable illnesses and death.⁵ While HIV itself, lack of receipt of ART, or side-effects from ART may contribute to these disparities, the lived experience of ongoing and past trauma (individual, family, community and historical trauma) are increasingly recognized as key drivers of these preventable deaths and health disparities.⁶ This knowledge offers new opportunities for intervention.

People living with HIV experience far higher rates of trauma and trauma-associated health conditions

Trauma and post-traumatic stress disorder (PTSD) are known to be significantly higher among people living with HIV compared to the general population. For example, a meta-analysis of studies of U.S. women living with HIV demonstrated an estimated prevalence of current PTSD of 30%, over 5 times that in the general population of women.⁷ Men living with HIV also experience highly disproportionate rates of PTSD.⁸ High rates of trauma and PTSD likely stem from disproportionately high rates of trauma experienced by people living with HIV, resulting from sexual and gender-based violence, experiencing life-threatening illness, deaths of close friends and family, stigma, and discrimination.

Trauma and PTSD, in general, are well known to contribute to higher rates of physical and psychological diseases. Studies over the past two decades have documented direct associations between chronic adult health conditions and significant trauma in childhood, also known as adverse childhood experiences (ACEs).⁹ A recent study from the Centers for Disease Control and Prevention (CDC) estimates that ACEs are the underlying cause of 13% of adult heart disease, 14% of stroke, 24% of asthma, 27% of chronic lung disease, 24% heavy drinking, 33% of cigarette smoking, and 44% of depression.¹⁰ In another recent

study, compared to adults who have no ACEs, adults who had more than four ACEs were 87% more likely to experience adult asthma, 47% more likely to experience cardiovascular disease, and 400% more likely to experience depression.¹¹ Research has linked similar poor health consequences to unaddressed trauma stemming from experiences of racism, poverty, state violence, and policing.¹² It is thus not surprising that people with HIV experience such high rates of trauma-related medical and psychological illness. It is important to note that adverse childhood experiences and other forms of childhood and adult trauma are also known to predispose individuals to HIV risk and acquisition.¹³

HIV exists in a syndemic with other infectious diseases, poverty, unemployment, and other factors where trauma and these health threats interact to magnify negative health outcomes. Therefore, broader solutions are needed including:

- Adopting trauma-informed primary care as a standard practice;
- Requiring and providing resources to clinics and health systems to track and report on the prevalence and outcomes of trauma-related preventable illnesses known to disproportionately affect people living with HIV;
- Looking beyond the treatment of disease to invest more in disease prevention and health promotion, such as expanding access to smoking cessation services, improving access to healthy foods, and expanding opportunities for recreation;
- Committing to representation so that people providing health and social services come from and are responsive to the communities they serve; and
- Addressing housing and economic insecurity, along with stigma and discrimination as part of a health promotion strategy.

Note: See citations on page 8

to ways in which HIV and the treatment of HIV are distinct from or exacerbate co-morbid conditions associated with aging need answers.

In addition to the National HIV/AIDS Strategy's commitment to developing a Quality of Life indicator and our earlier recommendation that HHS develop new whole person health guidelines, HRSA's HIV/AIDS Bureau should lead a cross-HHS effort to develop validated and standardized screening tools¹⁶ that measure elements of quality of life and work in tandem with these other tools to improve quality of life. This should build upon and adapt existing screening tools and consider metrics related to resiliency, non-HIV-related illness, mental health, social engagement and life satisfaction, and other metrics of quality of life, all while recognizing the need for as few metrics as possible to ensure their use in clinical practice. CDC also should partner with people living with HIV and public health professionals to consider ways in which the Medical Monitoring Project (MMP)¹⁷ can provide information about quality of life and consider potential additions to future samples that focus more on non-medical aspects of quality of life. In all of these efforts, whether it is recommended actions by NIH, HHS, HRSA, CDC, or other agencies, a critical resource to enhance success is to move beyond just consultations with constituencies of people living with and affected by HIV to funding partnerships with organized networks of people living with HIV to be actively engaged in carrying out these activities.

THE TIME IS NOW

It is exciting to think that it may be possible to end the HIV epidemic in the United States. Progress often has been made by focused and strategic action that has included advocacy, research, ever improving clinical care, and the development of networks of community-based services. Fundamental to all of this has been the leadership of people living with HIV. As we celebrate how far we have come, people living with HIV are once again calling for a course correction and demanding a reinvigoration of the partnerships that historically have been critical to much of our progress between people living with HIV and researchers, providers, and program administrators. They are reminding policymakers and the public that our ultimate goal is to adopt a holistic vision for a high-quality life for those who are living with HIV.

ENDNOTES

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