

MAY 2021

# HIV POLICY IN THE UNITED STATES

## MEETING THE NEEDS OF PEOPLE AGING WITH HIV

ON THE PATH TO ENDING  
THE HIV EPIDEMIC



MAY 2021

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**With high-quality care and ongoing treatment, people living with HIV can live long and healthy lives.** Someone who is newly diagnosed with HIV and soon receives antiretroviral therapy (ART) can live a typical lifespan. This is incredible news that few could have imagined 30 years before effective HIV treatment, or “highly active antiretroviral therapy” (HAART), became available. Nonetheless, too many people who are aging with HIV feel invisible within the broader HIV community and are deeply hurt that their issues and needs appear to be low on the advocacy agenda and ignored by policymakers. Today, more than half of people living with HIV in the United States are aged 50 or older, and a growing number of people are living and aging with HIV into their 70s and beyond.<sup>1</sup> As the new Administration re-establishes the White House Office of National AIDS Policy (ONAP) and assesses the state of HIV in the United States, this provides a fresh opportunity to spotlight the needs of people who are aging with HIV and deliver necessary corrective policy actions.

## **POLICY ACTION IS NEEDED TO IMPROVE THE HEALTH OF OLDER PEOPLE LIVING WITH HIV**

**A greater focus on HIV and aging is needed. To meet the needs of older people living with HIV, policy action must address the following:**

1

**DEVELOP** models of care and prevention for people aging with HIV and train and equip the clinical and non-clinical workforce.

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2

**EXPAND** opportunities for older people living with HIV to make social connections through community-based programs that address isolation, stigma, and trauma.

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3

**MAINTAIN** Medicare Part D drug access protections (e.g., Six Protected Classes) and expand focus on high-quality care and quality of life.

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4

**ALLOCATE** more funding to programs that support financial security and access to employment, housing, food, and public benefits for the aging HIV population.

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**PROMOTE** the meaningful participation of older people living with HIV in the Ending the HIV Epidemic (EHE) Initiative and in broader advocacy efforts.

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**ENDING THE HIV EPIDEMIC IN THE UNITED STATES INVOLVES MORE THAN REDUCING NEW HIV TRANSMISSIONS AND SUPPORTING PEOPLE WITH HIV TO ACHIEVE VIRAL SUPPRESSION.**

The burdens of HIV, aging, and related health comorbidities, combined with the social and structural challenges that people aging with HIV face, necessitate not only a focus on HIV-related outcomes, but also a comprehensive response aimed at treating comorbidities and improving long-term health and quality of life. Concerted action is needed to meet the needs of older people living with HIV. This must include programs across the federal government and a commitment to health equity and intersectional policy approaches that take into account the overlapping systems of discrimination or disadvantage (e.g., race, class, sex, gender identity, sexual orientation, immigration status) impacting the lives of older people living with HIV.

Older people living with HIV include many long-term survivors who have lived with HIV for more than ten years, as well as older people who have been diagnosed with HIV more recently. Some long-term survivors were diagnosed with HIV before HAART became available, and others were diagnosed after 1996, when HAART became more widely available.<sup>2</sup> It is possible to be a long-term survivor and be under the age of

50. This issue brief focuses on people aged 50 and older regardless of whether they are long-term survivors, but it is acknowledged that the aging process among long-term survivors and others under the age of 50, including people living with HIV through perinatal transmission, warrants attention. Long-term survivors from the pre-HAART era often have distinctive experiences compared to those who came later. These survivors received their diagnosis when HIV regularly resulted in death, and many spent the early years after their diagnosis believing they would die young and watching partners and friends die from AIDS. As such, they often experienced considerable trauma that is difficult to resolve. Some struggle with mental health problems as a result of this trauma, and those who did not plan for a future may now struggle with financial instability.

There are a number of common challenges that older people living with HIV face as the result of HIV, aging, and the complex interplay of HIV and aging-associated factors. Yet these challenges are sometimes obscured when the focus is on HIV viral suppression as the primary health outcome. Compared to all people with HIV, people with HIV aged 55 and older have higher rates of viral suppression and retention in care.<sup>3</sup> In 2018, 64 percent of people with HIV aged 55 and older

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**OLDER PEOPLE LIVING WITH HIV INCLUDE MANY BUT NOT ALL LONG-TERM SURVIVORS**

**WHO HAVE LIVED WITH HIV FOR MORE THAN TEN YEARS. SOME LONG-TIME SURVIVORS WERE DIAGNOSED WITH HIV BEFORE HIGHLY ACTIVE ANTIRETROVIRAL THERAPY (HAART) BECAME AVAILABLE, AND OTHERS WERE DIAGNOSED WITH HIV AFTER HAART BECAME AVAILABLE.**

**OLDER PEOPLE WITH RECENTLY DIAGNOSED HIV ARE PEOPLE WHO ARE AGED 50 OR OLDER AND HAVE BEEN LIVING WITH HIV FOR LESS THAN TEN YEARS.**

## LEVERAGING RESOURCES ACROSS THE FEDERAL GOVERNMENT

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**Many programs in the federal government exist to support older people. It is important to take advantage of all resources, not just federal HIV programs, to meet the needs of people aging with HIV.** Educating HIV stakeholders about resources that already exist for aging populations can help more people living with HIV access critical services without having to create new services specifically for this population. The following are just a handful of examples of federal resources that focus on older people:

**Program of All-Inclusive Care for the Elderly (PACE):** The Program of All-Inclusive Care for the Elderly provides comprehensive medical and social services for certain frail, older people living in the community, most of whom are dually eligible for both Medicare and Medicaid. An interdisciplinary team (including not only doctors, nurses, dietitians, physical therapists, and social workers, but also activity coordinators, home care liaisons, occupational therapists, personal care attendants, and drivers) provides older individuals enrolled in PACE with coordinated care. PACE provides services primarily in adult day health centers, and those services are supplemented by in-home and referral services in accordance with the enrollee's needs. Most financing for PACE services comes from fixed monthly Medicare and Medicaid payments for each enrollee, which allows providers to cover needed services, including social determinants of health, rather than only those services reimbursable under Medicare and Medicaid fee-for-service plans.

**Older Americans Act (OAA):** The Older Americans Act funds a range of critical services to help older people live independently in their homes and communities. These services include home-delivered and congregate meals, job training, senior centers, health promotion, benefits enrollment, caregiver support, transportation, and more.

**Administration for Community Living (ACL):** The Administration for Community Living was created in 2012 as a new agency under the United States Department of Health and Human Services (HHS) to coordinate operations of federal agencies that promote community-based living (e.g., the Administration on Aging, the Administration on Disabilities, and the Center for Integrated Programs). ACL funds services and supports provided primarily by states and networks of community-based organizations, and it works to ensure that the preferences and the needs of older adults and people with disabilities are at the center of the system of services and supports. ACL's health and wellness programs address behavioral health, prevention of injuries and illness, chronic disease self-management, and other issues. Its 'employment first' initiatives help to eliminate barriers to employment and help people with disabilities access meaningful and integrated employment. ACL's programs also address abuse and rights violations of older people and people with disabilities, empower individuals to advocate for their own needs, provide grants and technical assistance to improve business practices of community-based organizations, and fund research and development of evidence-based approaches.

**Housing Programs:** Low-income housing programs are available for older people through the United States Department of Housing and Urban Development (HUD). There are many HUD programs with varying age and income eligibility requirements. HUD's Section 202 Supportive Housing for the Elderly program addresses both affordability and the connection between housing and supportive services. Under the program, HUD provides interest-free capital advances to nonprofits to develop housing that offers project-based rental assistance and supportive services for very low-income elderly residents.

were virally suppressed, whereas only 56 percent of all people with HIV were virally suppressed.<sup>4</sup> Metrics of viral suppression and retention in care, however, do not provide a complete picture of the health and well-being of older people living with HIV. Older people living with HIV are more likely to have multiple comorbidities that impact their health and quality of life. People aging with HIV also face social and structural challenges that are too frequently overlooked and ignored. More focused efforts are needed to understand and address the issues facing the aging population of people living with HIV and to support effective advocacy and programs for and by older people living with HIV.

## AGING-RELATED CHALLENGES AMONG PEOPLE LIVING WITH HIV

While rates of sustained viral suppression must still be improved for older people living with HIV, it is important to embrace a holistic approach to the health of this population. Older people living with HIV face physical

health challenges. These include both HIV-related and other comorbidities. Compared to their age peers who do not have HIV, older people living with HIV have higher rates of comorbidities associated with aging, such as cardiovascular disease, liver disease, diabetes, cancer, and neurocognitive impairment,<sup>5,6</sup> as well as higher rates of geriatric syndromes, such as falls and frailty.<sup>7</sup> Multiple comorbidities can place older people living with HIV at an increased risk of functional decline and disability.<sup>8</sup> Because of multiple comorbidities, concurrent use of multiple medications (also known as polypharmacy) is common among older people living with HIV, which increases the risk of drug-drug interactions.<sup>9</sup> Older people living with HIV also deal with various oral health problems, including tooth loss, receding gums, and deterioration of the jawbone, which can cause pain and challenges with eating and maintaining healthy nutrition. As a result, many have dental bridges, partial dentures, or full dentures. Furthermore, many older people with HIV face mental health issues, such as depression and substance use disorders.<sup>10,11</sup> For example, rates of depression among

## CRITICAL NEEDS FOR RESEARCH ON HIV AND AGING

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**The aging of people living with HIV presents new challenges in how to address HIV and aging-related conditions, such as health comorbidities, concurrent use of multiple medications, and psychosocial factors, and how to develop models for clinical care and community support.** More research is needed to better understand the interaction of HIV and aging and identify strategies for prevention and treatment of aging-related conditions.

## ACCELERATED VERSUS ACCENTUATED AGING

Current research evidence is insufficient to determine if HIV leads to accelerated aging or accentuated aging. Accelerated aging can be defined as an age-related decline that arises earlier than expected and increases progressively. In contrast, accentuated aging is an increased burden of disease multimorbidity.

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Scientists acknowledge that more research is needed to answer questions about accelerated aging. It is difficult to attribute accelerated aging to HIV because people living with HIV also experience higher rates of other conditions, such as poverty, diabetes, depression, hepatitis co-infection, and substance use disorders, which impact aging-related health outcomes and call for syndemic approaches to understanding these interrelated and overlapping factors. Additionally, the risk for poorer aging-related outcomes may be greater among older people living with HIV because of less than optimal antiretroviral medications in the early years of the HIV epidemic, long-term toxicity of some antiretroviral medications, lack of consistent viral suppression over time, and the compounding effects of HIV and aging on chronic inflammation. For example, inflammation results from the immune system of people living with HIV being constantly activated as the body works to fight HIV. A chronically inflamed immune system, in turn, has been associated with cardiovascular disease, cancer, and other comorbidities that appear in higher rates among people living with HIV.

Further studies surrounding the aging process should assess how novel, integrative biomarkers can be used to meaningfully predict an individual's biological age and to understand the effects that HIV and subsequent treatment have on the natural aging process. There is also a need for longitudinal cohort studies of people living with HIV with sociodemographically-matched control groups.

## FUTURE RESEARCH DIRECTIONS

Other priority areas for clinical research include (1) understanding biological and neurological mechanisms behind aging with HIV to better inform targeted and efficacious treatments and regimens for HIV, (2) investigating feasible and sustainable interventions to promote better daily function and health outcomes for people living with HIV, and (3) increasing implementation science to enhance clinical experience and treatment for older people living with HIV. Significant gaps exist in research on HIV and aging among women and transgender people, and more research is needed on HIV and aging among gay and bisexual men and among heterosexual men. Aging as a woman comes with challenges that men do not experience, such as experiencing menopause and other sexual and reproductive health changes and having a disproportionate burden of certain chronic comorbidities. While some studies have reported that, compared to women who do not have HIV, women living with HIV experience menopause at an earlier age and experience heightened menopausal symptoms, there is a need for more studies on older women living with HIV and dealing with menopause. Studies should assess the safety and efficacy of hormone therapy on symptoms of menopause, cardiovascular risk, and bone disease among this population. There is also a need for studies on hormone therapy among transgender people aging with HIV, aging women who are maintaining their HIV and have caretaking responsibilities, and women and transgender people diagnosed with HIV in old age. Additional research should be conducted to study the experiences of older people living with HIV in congregate living facilities, with a focus on the experiences of women, transgender people, gay and bisexual men, and people of color. Moreover, research is needed on the long-term effects of COVID-19 on older people living with HIV and on social determinants of health among this population.

**Sources:** (1) Sundermann EE, et al. Current challenges and solutions in research and clinical care of older people living with HIV: Findings presented at the 9th International Workshop on HIV and Aging. *AIDS Res Hum Retroviruses* 2019;35(11-12): 985-998. (2) Palella FJ, et al. Non-AIDS comorbidity burden differs by sex, race, and insurance type in aging adults in HIV care. *AIDS* 2019;33(15):2327-2335. (3) Adam GP, et al. Strategies for improving the lives of US women aged 40 and above living with HIV/AIDS: An evidence map. *Syst Rev* 2018;7:25.

older people living with HIV are five times greater than among peers who do not have HIV.<sup>12</sup> At the same time, older people living with HIV are less likely to receive mental health care than their younger counterparts.<sup>13</sup> In fact, older people living with HIV may confront additional challenges getting into care due to stigma, trauma, isolation, and lack of support from their family, friends, and community.<sup>14,15</sup>

## POLICY ACTIONS THAT SUPPORT OLDER PEOPLE LIVING WITH HIV

Big and complex issues can immobilize policymakers and lead to inaction. There are so many actions and initiatives that could be implemented to better support people who are aging with HIV that it is hard to move forward. The following priorities offer the HIV community, policymakers, and program administrators a place to start:

### 1

#### **Develop models of care and prevention for people aging with HIV and train and equip the clinical and non-clinical workforce.**

While federal policy cannot overcome every challenge, federal leadership is essential. The federal government must invest resources and implement approaches through HIV and health programs to better support older people living with HIV and their health care providers. Priority programs include programs within the Health Resources and Services Administration (HRSA), HIV prevention programs at the Centers for Disease Control and Prevention (CDC), HIV research programs at the National Institutes of Health (NIH), and health programs at the Department of Veteran Affairs (VA).

HRSA's Ryan White HIV/AIDS Program is a federal program that provides a

comprehensive system of care for people living with HIV and is uniquely positioned to lead the way in better meeting the needs of people living with HIV as they age. Ryan White HIV/AIDS Program services that are critical to helping older people living with HIV overcome challenges include (1) physical health, oral health, mental health, and substance use disorder services, (2) case management, care coordination, and insurance navigation, (3) medical transportation, emergency housing, and food services, and (4) cost-sharing assistance. Additionally, the Ryan White HIV/AIDS Program works to build capacity within the health system for supporting the aging HIV population, and the program can lead the way on addressing psychosocial issues among older people living with HIV and promoting the adoption of trauma-informed care approaches for this population.

Ryan White HIV/AIDS Program-funded clinics and providers are experienced in providing complex care provision for people living with HIV. The HIV/AIDS Bureau (HAB) of HRSA, which administers the Ryan White HIV/AIDS Program, works with these clinics and providers to identify and share effective strategies to meet the unique needs of older people living with HIV. Over the past year, HRSA HAB has supported clinics and providers by holding an Aging Institute at the 2020 National Ryan White Conference on HIV Care and Treatment and by developing two reference guides to build and expand the knowledge and practice of health care teams in serving people aging with HIV. The first reference guide, *Optimizing HIV Care for People Aging with HIV: Incorporating New Elements of Care*, identifies commonly occurring health care and social needs of people aging with HIV and highlights the screenings and assessments for these needs.<sup>16</sup> The second reference guide, *Optimizing HIV Care for People Aging with HIV: Putting Together the Best Health Care Team*, discusses how all members of the health care team can contribute to the care of people aging with HIV.<sup>17</sup>



Older people living with HIV have physical and mental health needs that are not fully addressed in the current health system. The complexity of these needs necessitates a more individualized, multidimensional approach to providing care. A number of approaches have been proposed, including educating HIV and primary care providers about aging and aging-related conditions, incorporating geriatric consultation and assessment into HIV care, and providing older people living with HIV with enhanced care coordination and linkage to community organizations that serve older individuals. Meeting the needs of older people living with HIV often requires a multidisciplinary care team, including primary care providers, HIV specialists, and geriatricians, as well as therapists and social workers, depending on the circumstances.

The Ryan White HIV/AIDS Program needs continued investment and improvement. In addition, the Ryan White HIV/AIDS Program must build upon its AIDS Education and Training Center (AETC) program, the Special Projects of National Significance (SPNS) program, and other efforts to develop innovative models of care for older people living with HIV and to ensure that the clinical and non-clinical workforce is trained and equipped to serve these people as they age. Programs at CDC, NIH, and the Department of Veterans Affairs also have roles in supporting effective approaches for older people living with HIV. Policy action is needed to:

- **Increase funding for the Ryan White HIV/AIDS Program and make changes within and to the program that support older people living with HIV.** Congress must continue its commitment to the Ending the HIV Epidemic (EHE) Initiative and increase funding for the Ryan White HIV/AIDS Program. The Ryan White HIV/AIDS Program is essential to meeting the physical, mental, and oral health care needs of older people living with HIV. Going forward, it is important to ensure that resources are being optimally used

for the services that people aging with HIV increasingly find that they need. Some services for which there is particular unmet need are mental health services, oral health services, and non-medical supportive services, including housing and employment services. While the 75/25 rule requires that at least 75% of funds under Parts A and B of the Ryan White HIV/AIDS Program and funds for early intervention services under Part C be applied to core medical services and no more than 25% of those funds be applied to supportive services, a waiver for this rule is available that, if granted, allows for more than 25% of funds to be used for supportive services. Ryan White HIV/AIDS Program recipients do receive waivers, and more recipients should use the waiver process to facilitate the expansion of supportive services within the program, which are necessary for improving access to and retention in care. In addition to the waiver process being a way to accomplish structural change, structural changes can be made through administrative action or through legislative action, such as reauthorization of the Ryan White HIV/AIDS Program. A needed structural change that can be made administratively or legislatively is the inclusion of employment services as an allowable non-medical supportive service. Although many changes can be made through administrative action, reauthorization would provide an important opportunity to improve the Ryan White HIV/AIDS Program so that it better meets the needs of people aging with HIV. For example, the Ryan White HIV/AIDS Program is prohibited by law from paying for inpatient care. Given that people living with HIV continue to be hospitalized at high rates and their hospitalization rates increase with older age, inpatient care may be a particular need for some older people with HIV who are uninsured. Changing the law to permit the Ryan White HIV/AIDS Program to pay for inpatient care would require reauthorization or other legislative action.<sup>18</sup>

- **Expand the geriatrics and HIV workforces and create opportunities for improving their knowledge, skills, and collaboration in the care of older people living with HIV.** The United States faces a critical shortage of doctors who specialize in geriatrics, even as nurse practitioners fill some of this gap by specializing in gerontology and delivering critical outpatient care to older people.<sup>19</sup> Likewise, fewer doctors are pursuing careers in HIV, as evidenced by the fact that more than one-third of Infectious Diseases fellowship programs did not fill their available training slots in 2019.<sup>20</sup> Many HIV providers also have aged and retired. The transition to new providers can sometimes be unsettling for older people living with HIV. The shift to deliver more HIV care through primary care providers, despite its many advantages, has raised yet another challenge for some older people used to meeting regularly with their infectious disease specialists. In addition to providing more resources, such as educational loan repayment programs, to incentivize health care professionals to work in the geriatrics and HIV fields, there is a need for creating more educational opportunities for HIV providers to learn about aging and to acquire the skills needed to treat aging-related syndromes. Also, there is a further need for adapting care models by embedding geriatricians within HIV clinics and primary care practices. Some opportunities and resources already exist. For example, HRSA, through its Bureau of Health Workforce, funds the Geriatrics Workforce Enhancement Program and the Geriatrics Academic Career Award Program. As part of the Ryan White HIV/AIDS Program, the Northeast/Caribbean AETC has developed a Care of People Aging with HIV Toolkit, which provides links to screening and assessment instruments and to programs and papers that offer clinically useful materials. The National HIV Curriculum, funded by the AETC Program, provides ongoing, up-to-date information, including a

special topic on “HIV in Older Adults,” needed to meet the core competency knowledge for HIV care. More funding for the AETC program could be used to train both clinical and non-clinical providers to provide appropriate services and supports for older people living with HIV. The SPNS Program also can play a role in developing and evaluating new approaches to both clinical and supportive care delivery for older people living with HIV.

- **Provide more resources for prevention and treatment messaging, healthy aging campaigns, and research focused on older people living with HIV.** People aged 50 and older accounted for one in six new HIV diagnoses in the United States in 2018.<sup>21</sup> HIV testing and prevention services may not adequately reach older people because health care providers may mistakenly assume that older people are not sexually active or because some older people may not perceive themselves as at risk for HIV. People aged 50 and older also may not always see themselves as old, which raises challenges for engaging older people living with HIV in geriatric HIV programs and other aging programs. It is important that CDC supports the development and delivery of culturally and linguistically appropriate prevention and treatment messaging for older people, especially older people of color and lesbian, gay, bisexual, or transgender (LGBT) older people. More funding should be directed toward launching social marketing campaigns that address HIV, aging, and related stigma. These campaigns should target the general public and priority populations. Efforts also should focus on encouraging health care providers to talk with older people about drug use and sexual behaviors and to offer appropriate HIV testing and status-neutral prevention and care services. NIH should be appropriately funded to engage in coordinated cross-division research focused on older people living with HIV, including research on

# GOLDEN COMPASS PROGRAM

## PROVIDES A SUCCESSFUL MODEL OF CLINICAL SERVICES FOR PEOPLE AGING WITH HIV

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**A number of clinical programs have implemented care models to better meet the needs of people aging with HIV.** Programs like the Golden Compass Program in San Francisco have implemented a consultative model, where HIV clinical providers refer people living with HIV to geriatricians and other aging specialists. While geriatric consultative services may be embedded in or external to these programs and often include supportive services and linkage to community-based organizations, the foundation of a consultative model is the comprehensive geriatric assessment (CGA), which is a multidimensional, multidisciplinary diagnostic process focused on assessing an older person's medical, psychological, and functional capability in order to develop a coordinated and integrated plan for treatment and long-term follow-up focused on the individual's needs.

### THE 6Ms: AN APPROACH TO COMPREHENSIVE CARE FOR OLDER PEOPLE LIVING WITH HIV

Optimal care for addressing aging and HIV should embrace what geriatric HIV specialists call the 6Ms: matters most, mind, mobility, medications, multicomplexity, and modifiable factors.

- (1) Matters most** means that clinicians should have an understanding of the personal health goals and care preferences of the people to whom they provide care. Clinicians should align care with those goals and preferences.
- (2) Mind** refers to cognitive function and goes beyond depression and anxiety to thinking about and managing neurocognitive health and dementia. To promote cognitive function, clinicians must inquire about safety, including safe driving and considerations for safety and social support at home. It is also important to diagnose and treat mood disorders, explore how comorbidities and polypharmacy impact cognition, and encourage older people living with HIV to maintain physical, mental, and social activity to maintain cognitive function.
- (3) Mobility** refers to ensuring that older people living with HIV maintain their physical functioning, such as through regular exercise. A key component of mobility is fall prevention, including home safety assessments to ensure the home is safe from tripping and slipping.
- (4) Medications** are a reality for older people living with HIV, which can mean polypharmacy and drug-drug interactions. Clinicians should only prescribe necessary medications. Also, clinicians should consider opportunities to reduce the medications that a person aging with HIV must take and to discontinue prescriptions that could increase risk of falls or other adverse effects.
- (5) Multicomplexity** acknowledges the difficulty in managing comorbidities within complex social and living conditions. Clinicians should assess these conditions and help older people living with HIV manage comorbidities.

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**(6) Modifiable** means prioritizing interventions that target the most modifiable factors that can impact multiple systems. This includes encouraging regular physical activity, healthy diet, discontinuation or reduction of substance use, meaningful social connections, and the development of positive coping skills for stress management.

## COMPONENTS OF THE GOLDEN COMPASS PROGRAM

Drawing on the 6Ms, the Golden Compass Program at the Ward 86 outpatient HIV clinic at San Francisco General Hospital was launched in January 2017 as a geriatric HIV program designed to help older people living with HIV navigate their golden years. The program involves a team of medical doctors, including a medical director, cardiologist, and geriatrician, as well as a registered nurse, a pharmacist, a program coordinator, and a medical assistant. People who participate in the program maintain their primary care provider, and they have consultations with an HIV-focused geriatrician and cardiologist in the same familiar clinic environment. The Golden Compass Program is framed around the idea of a compass and focuses services around four points:

- (1) Heart and Mind (Northern Point)** focuses on comorbidities and includes on-site cardiology, cognitive evaluations, and brain health classes;
- (2) Bones and Strength (Eastern Point)** focuses on bone health, fitness, and physical function, through exercise classes and on-site geriatric consultation;
- (3) Dental, Hearing, and Vision (Western Point)** ensures appropriate screenings for dental concerns and sensory impairment and provides linkage to and navigation assistance for dental, audiology, and optometric/ophthalmology services; and
- (4) Networking and Navigation (Southern Point)** focuses on social and community-building activities.

## OUTCOMES OF THE GOLDEN COMPASS PROGRAM

In the first year and a half of the Golden Compass Program, 198 people living with HIV aged 50 years or older participated in the program. Over 90% of participating providers and people living with HIV were satisfied with the program. Provider adoption was high, with 85% of providers referring at least one patient to the geriatrics clinic and 59% of providers referring to the cardiology clinic. Co-location of services, pharmacy and geriatric assessments, and social support from classes were valued.

**Sources:** (1) Siegler EL, et al. Older people with HIV are an essential part of the continuum of HIV care. *J Int AID Soc* 2018;21(10):e25188. (2) Siegler EL, Brennan-Ing M. Adapting systems of care for people aging with HIV. *J Assoc Nurses AIDS Care* 2017;28(5):698-707. (3) Erlandson KM, Karris MY. HIV and aging: Reconsidering the approach to management of comorbidities. *Infect Dis Clin N Am* 2019;33(3):769-786. (4) Greene M, et al. The Golden Compass Program: Overview of the initial implementation of a comprehensive program for older adults living with HIV [published online July 27, 2020]. *J Int Assoc Provid AIDS Care*. doi: 10.1177/2325958220935267.

psychosocial issues and implementation science to facilitate uptake and sustainability of geriatric HIV programs or other aging programs among people living with HIV and among health care providers. The Department of Veterans Affairs is leading the way in HIV testing, prevention, treatment, and research for veterans. The VA should continue to investigate best practices for connecting veterans to HIV and aging services and serve as a model for implementing these services in other settings.

## 2

### **Expand opportunities for older people living with HIV to make social connections through community-based programs that address isolation, stigma, and trauma.**

Social isolation refers to living without companionship, social support, or social connectedness and has been associated with decreased quality of life, poor health, increased health care utilization, functional decline, and premature death among older people.<sup>22</sup> People living with HIV are at increased risk of social isolation due to stigma and social rejection. Older people living with HIV are particularly vulnerable because they experience the dual threat of HIV stigma and ageism. Many of these people also have additional stigmatized identities related to their race, sexual orientation, gender identity, and other characteristics. Older people living with HIV, especially older people of color, experience higher rates of social isolation than their younger counterparts, with one study finding that more than 38 percent of older people and 54 percent of older people of color were at risk of social isolation compared with 25 percent of those aged 20 to 39.<sup>23</sup> Older people living with HIV, especially those who are women, people of color, or LGBT individuals,

experience various forms of trauma. Acknowledging and responding to trauma experiences of people aging with HIV is also essential for meeting their needs.

Social networks have been shown to be an important element in the lives of people living with HIV. People living with HIV who report adequate social and emotional support from these networks are more likely to be in care, adhere to treatment, and have better physical and mental health outcomes.<sup>24,25,26</sup> Family, friends, and, to a lesser degree, neighbors play a significant role in the composition of social networks for people living with HIV. Since these traditional social networks are often inadequate, networks of people living with HIV (PLHIV networks) and community-based organizations, such as AIDS service organizations (ASOs), Area Agencies on Aging (AAAs), and faith-based organizations, are critical alternative sources of support. However, many older people remain disconnected from both traditional and alternative support networks. To address social isolation, stigma, and trauma among older people living with HIV, policy action is needed to:

- **Strengthen and expand PLHIV networks and increase funding for community-based organizations that provide social support services for older people living with HIV.** PLHIV networks are a key mechanism for enhancing support to older people living with HIV and can help to ameliorate negative experiences around aging with HIV. These networks must be bolstered now and into the future. More funding is needed for community-based organizations that serve the aging HIV population. Access to social support services is critical for older people living with HIV, so that they can build and maintain personal connections, stay active, and participate in their local communities. This may be particularly true for racial, sexual, and gender minorities who are more likely to be socially and financially isolated

## POSITIVE LIVING CONFERENCE ADDRESSES HIV, AGING, AND SOCIAL ISOLATION

**Okaloosa AIDS Support and Informational Services, Inc. (OASIS Florida), now in its 30th year of operation in northwest Florida, is dedicated to preventing HIV transmission and supporting all people who are affected by HIV. OASIS Florida has organized the Positive Living Conference since 1997.** This annual conference is the nation's oldest and largest gathering of people living with HIV and brings together approximately 450 attendees each year from all over the country. Over 95 percent of attendees are people living with HIV, and the vast majority of them are over the age of 50. The conference includes interactive workshops on different topics, such as "HIV and Aging" and "Healthy Relationships," and ends with an open mic session where all attendees are encouraged to share and be heard.

The Positive Living Conference and other conferences and networks for and by people living with HIV are critically important for combating social isolation among people aging with HIV and for addressing broader issues that they face. Many older people with HIV deal with stigma, loneliness, and depression in addition to physical health comorbidities. These issues are particularly challenging for those living in rural areas. Conferences and networks allow older people living with HIV to connect with and support each other, discuss relevant and interesting topics, and define their own agendas.

**Source:** Positive Living Conference. <https://aumag.org/2018/09/08/positive-living-conference-september-14-16/>.

from resources available to other groups. Faith-based organizations are made up of a large population of older people, and those providing HIV services are a critical lifeline for older people living with HIV, especially in communities of color.

- **Identify ways to leverage technology for social support and connection and to overcome barriers that older people living with HIV face in using technology.** The COVID-19 pandemic has led to a significant expansion in the use of telehealth services. Technology also can play an important role in providing social support services and addressing the isolation, stigma, and trauma that older people living with HIV experience. Services providers at community-based organizations should pursue opportunities to communicate with people using cell phones or social media and hold support groups and social activities online in a manner that

is consistent with federal and state laws and privacy protections. At the same time, many older people living with HIV lack access to technology or may be reluctant or unaccustomed to using it. Funding may be needed to provide necessary technology, education, and assistance to these individuals. More research on how older people living with HIV use or prefer to use technology also may be necessary.

### 3

**Maintain Medicare Part D drug access protections (e.g., Six Protected Classes) and expand focus on high-quality care and quality of life.**

Medicare, the federal health insurance program for people aged 65 and older,

as well as working age people with disabilities, is an important source of health coverage for people aging with HIV, both those who qualify because of age and those who qualify because of a disability. Medicare consists of several parts. Part A covers hospital care, while Part B covers physician services, outpatient care, and some home health and preventive services. Part C, called Medicare Advantage, is a voluntary managed care alternative to traditional Medicare coverage, and Part D is the voluntary outpatient prescription drug benefit. The majority of Medicare beneficiaries with HIV have low incomes that make them dually eligible for Medicare and Medicaid. Medicaid provides additional cost-sharing assistance and covers long-term services and supports (LTSS) that are not covered by Medicare. Medicare is now the largest source of federal financing for HIV care and treatment.<sup>27</sup> More than half of Medicare spending for beneficiaries living with HIV is Part D drug spending.<sup>28</sup>

Medicare Part D prescription drug plans currently are required to include at least two drugs per class on their formularies and to cover substantially all drugs in six protected classes, including antiretrovirals. The other protected classes are immunosuppressants, anticonvulsants, antidepressants, antineoplastics, and antipsychotics. There is an additional protection for HIV antiretroviral drugs: plans are not permitted to require prior authorization or step therapy for these medications. On the last day of the Trump Administration (January 19, 2021), the Centers for Medicare and Medicaid Services (CMS) announced changes to the Part D program that would allow participating Part D plans to disregard the protected classes policy and only cover one drug per class, with no exemptions for people currently taking a specific protected class status medication.<sup>29</sup> The proposed changes would have allowed Part D plans to begin limiting access to prescription drugs for five protected classes in 2022 and for antiretroviral drugs in 2023. In March 2021,

the Biden Administration rescinded these changes,<sup>30</sup> but since the protected class policy has been threatened with change or elimination since the establishment of the Part D program, it is necessary to guard against problematic new restrictions on drug coverage. Maintaining the protected class policy is particularly important for older people living with HIV because the policy ensures access to a broad range of drugs for the treatment of HIV and comorbidities. Older people living with HIV also have co-occurring mental health disorders, substance use disorders, and other health conditions that require various drug treatments. In addition to preserving Medicare drug access protections, CMS should consider opportunities to:

- **Refine quality measures, monitor social determinants of health, and support complex care management within Medicare.** CMS can take more proactive steps in promoting optimal care for older people, including those living with HIV. It is important to examine whether current reimbursement mechanisms adequately serve older people who have complex needs and may require more time with a health care provider. There are also opportunities for CMS to address the quality of health care services provided to Medicare beneficiaries and to refine the Star Rating System, which sets quality measures for Medicare Advantage and Part D plans and helps beneficiaries pick a plan based on quality performance. In addition to improving quality measures in the Star Rating System to better measure outcomes and incentivize value-based care, CMS should help Medicare Advantage and Part D plans focus on people with multiple chronic conditions and work with providers on integrating social determinants of health into electronic health records. Taking these steps is important for a wide range of Medicare beneficiaries, not just people living with HIV.

- **Support access to long-acting HIV products that could benefit older people living with HIV.** CMS, along with other payers and federal agencies, including HRSA, should ensure appropriate access to long-acting HIV treatment and prevention options, which do not require daily dosing. The Food and Drug Administration approved a long-acting injectable product for HIV treatment in January 2021, and more long-acting products for HIV treatment and prevention are under development as injections, implants, or oral medications. These products have the potential to facilitate greater adherence in ways that improve health and quality of life. For older people living with HIV to benefit from long-acting products, federal agencies should provide guidance to purchasers, prescribers, and the public on how the products will be evaluated and integrated into drug formularies.

## 4

### **Allocate more funding to programs that support financial security and access to employment, housing, food, and public benefits for the aging HIV population.**

Structural factors, such as poverty, unemployment, and lack of housing, contribute to new HIV transmissions and poor health outcomes. While people living with HIV who are employed have better adherence to medication and better physical and mental health outcomes,<sup>31,32</sup> people living with HIV often face significant barriers to entering or re-entering the workforce. These barriers include workplace discrimination and risking the loss of benefits or services from programs with income eligibility limits, such as Medicaid, the Ryan White HIV/AIDS Program, or the Supplemental Security Income (SSI) Program, if individuals earn too much income. Older people living with

HIV face additional employment challenges. Research from one study demonstrates that older age and HIV disease have independent and additive adverse effects on employment status, even though they are not an indication of low work functioning.<sup>33</sup> In a research study out of the United Kingdom, higher quality of life among people living with HIV was strongly associated with having paid employment, having a higher level of income, and not being on public benefits.<sup>34</sup>

Other major areas of concern for many older people living with HIV include food and housing insecurity and the management of finances and health care benefits. People living with HIV who are food insecure often forego critical medical care and are less likely to be virally suppressed.<sup>35</sup> Research has demonstrated relatively high levels of food insecurity among older people living with HIV, underscoring a need to implement targeted food assistance strategies for this group.<sup>36</sup> For many older people living with HIV, affordable and safe housing is difficult to obtain. Whereas those who are homeless or unstably housed have worse overall health outcomes, those moving into assisted living facilities or nursing homes face stigma surrounding HIV and, if they are LGBT individuals, homophobia or transphobia. Still another concern for people aging with HIV is navigating issues with public benefits like Social Security and Medicare benefits. To address these various structural challenges, policy action is needed to:

- **Create employment opportunities for people aging with HIV, including within the HIV workforce.** Federal agencies, including the Department of Health and Human Services, the Department of Housing and Urban Development, the Department of Labor, and the Department of Education, should coordinate to develop and fund a plan focused on promoting vocational training and employment opportunities for people aging with HIV, including within



## THE REUNION PROJECT AND TPAN COLLABORATE ON “POSITIVELY AGING”

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**Created in 2015, The Reunion Project (TRP) is a national alliance of long-term survivors of HIV working in collaboration with local and national HIV advocates, providers, and researchers.** Between 2015 and 2018, TRP tasked local leaders in six major urban cities with organizing local town halls and other events in an effort to reunite and mobilize survivors. In March 2018, TRP also organized a national roundtable forum consisting of survivor experts, long-term survivors, caregivers, and others. The main objective of the forum was to create a powerful and sustainable Coalition of Survivorship. Following the forum, four stand-out issues to be addressed going forward were identified:

- (1) Research regarding actual lived experiences**, the impact of technology, aging, and comorbidities, and differing effects across different geographical regions;
- (2) Systems-based and individual/community-based programs** concentrated on awareness, skills, and support for mental health, well-being, and economic justice;
- (3) Creating safe spaces, networks, and wider-reaching partnerships** to increase access to information, representation, and justice; and
- (4) Advocacy to achieve the above-stated goals and other goals.**

In May 2019, TRP joined with the Test Positive Awareness Network (TPAN) to create *Positively Aging*, a collaboration designed to address the needs of older people living with HIV. *Positively Aging* seeks to innovate the delivery of TPAN’s direct services (medical care, mental health services, case management, and social activities) in Chicago to older persons living with HIV, engage older persons living with HIV through an expansion of TRP’s national peer-driven support network, and disseminate educational resources about HIV and aging to a national audience through TPAN’s magazine, *Positively Aware*.

**Sources:** (1) Fawcett D. The Reunion Project seeks to build an HIV research agenda for long-term survivors. *TheBodyPro*. October 1, 2018. <https://www.thebodypro.com/article/the-reunion-project-seeks-to-build-an-hiv-research>. (2) Positively Aging. <https://www.tpan.com/positively-aging>.

the HIV workforce. These agencies must work with state and local government partners, community-based organizations, and people living with HIV to create and implement interventions that provide job-related information, skills, and resources to people aging with HIV, support these individuals to obtain and maintain employment, and focus on ensuring that policies do not deter them from engaging in the workforce. It is also important to address stigma and discrimination that older and other people living with HIV face due to their

HIV status or LGBT identity when seeking services from workforce development or vocational rehabilitation programs. Additionally, addressing the employment needs of young and middle-aged people living with HIV can serve as prevention of unemployment, underemployment, and economic insecurity as these people age into their older years. The COVID-19 pandemic has increased economic insecurity and also increased the need for employment-related services and resources.

- **Increase funding for food assistance for people aging with HIV.** Increased funding for food and nutrition services is critical to meeting the needs of low-income people living with HIV as they age. The need for these services is only heightened by the public health and economic crises brought on by the COVID-19 pandemic. Due to these crises, food and nutrition programs across the country have experienced an unprecedented surge in requests for home-delivered meals and other services from older adults, including older people living with HIV, who are homebound and/or economically vulnerable. Investment in research is also needed to identify the scope of food insecurity among older people living with HIV and to understand the impact of different food interventions for this population. HRSA's HIV/AIDS

Bureau should continue to monitor the provision of food and nutrition services for all people in the Ryan White HIV/AIDS Program and track related health outcomes and cost savings. Given that funding decisions for Ryan White HIV/AIDS Program services are made at the local or state level, it is important to incorporate information on the provision of food and nutrition services for different age groups into the needs assessment process that Ryan White Planning Councils conduct each year.

- **Increase financial support for federal and state initiatives to address homelessness and housing insecurity among people aging with HIV.** The Housing Opportunities for Persons with AIDS (HOPWA) program has never been funded to meet the level of need. There is

## **OLDER WOMEN EMBRACING LIFE (OWEL) FOCUSES ON THE NEEDS OF OLDER BLACK WOMEN LIVING WITH HIV**

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**Older Women Embracing Life (OWEL) is a network of older women in the Mid-Atlantic region that is leading efforts to meet the comprehensive needs of women, especially Black women, living and aging with HIV.** OWEL was formed in 2005 because of the limited awareness of the impact of HIV on older women. Older women often face challenges disclosing their HIV status due to stigma and fear; they also lack opportunities and venues for connecting with each other and receiving emotional support. In many communities, support groups are not readily available for older women living with HIV. Social service and health care providers also may not be aware of the unique needs of this population. This is particularly true for older Black women, who are the group that OWEL primarily serves. In addition to dealing with HIV and aging, these women face challenges related to their race and sex, may have caregiving responsibilities taking care of children, grandchildren, or elderly parents, and often confront other issues.

Despite challenges associated with HIV and aging, the goal of OWEL is to foster a community of women who are living full, productive, and happy lives. To achieve this goal, OWEL develops and implements projects and programs that are aimed at promoting women's physical, emotional, spiritual, and mental health and helping women access services and manage various other aspects of their lives. These projects and programs include:

*Continued on next page*

## SUPPORT GROUPS AND INTERVENTIONS

OWEL provides mentoring and support to women struggling with the realities of an HIV diagnosis. Since its formation, OWEL has offered monthly support groups for women living with HIV. These support groups typically meet at local churches and provide social support and networking for women living with HIV, as well as opportunities to educate and train women about HIV care and treatment, supportive services, civic engagement, and other topics. In addition to support groups, OWEL has delivered evidence-based interventions, including Sister to Sister and the Women Involved in Life Learning from Other Women (WILLOW) intervention. These interventions are aimed at increasing self-efficacy in HIV management and HIV prevention.

## PEER NAVIGATION SERVICES

Members of OWEL also provide peer navigation and support services to help women with medical appointments and medication adherence as well as to foster a sense of community and connection. These services may include sending text messages to remind or encourage women to take their medication, making phone calls to let them know that someone is thinking about them, and checking in about experiences with health care providers. OWEL also holds interagency roundtables to bolster individuals' care plan development and compliance.

## HEALTH FAIRS, WORKSHOPS, CONFERENCES, AND COMMUNITY EVENTS

The Legends and Young'uns Conference is an annual regional conference organized by OWEL that brings together women living with HIV, including long-term survivors and those who are newly diagnosed with HIV, to address the unique needs these women have. Through presentations and interactive workshops, the conference focuses on a variety of issues, such as the clinical manifestation of HIV, retention and engagement in care, reproductive health, behavioral health, and pre-exposure prophylaxis (PrEP). OWEL also organizes an annual campaign called Teach and Test, in which its members conduct outreach to older people in residential high-rise buildings and senior service facilities about testing for HIV and living with HIV. Similarly, OWEL holds events such as Testing for Turkeys, which offers free HIV and hepatitis C testing and gives away turkeys for Thanksgiving, and a Speakers Bureau, which involves women with HIV going to places of worship and other community settings to share their stories. These events are also a way to disseminate information about local organizations and connect women to resources in the community.

## ADVOCACY AND RESEARCH

Working closely with health departments and academic institutions, OWEL advocates for research on older women living with HIV and for the inclusion of these women in public health activities and data reporting. OWEL seeks to make sure that older women are part of HIV research and engages researchers around involving these women from the conception of research questions through evaluation and study completion. Additionally, OWEL educates women on the importance of participation in research studies and helps to recruit women for studies and share the results of studies with women.

**Sources:** Older Women Embracing Life, Inc. <http://www.owelinc.org>.

also increasing need for housing supports amid the COVID-19 pandemic. More funding should be allocated for HOPWA and for housing programs that support both transitional and subsidized housing for older people living with HIV.

- **Expand navigation services that help older people living with HIV learn about and resolve issues with Social Security and Medicare benefits.** Some older people living with HIV qualify for disability benefits administered by the Social Security Administration, namely Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). SSDI provides cash assistance to people with disabilities, with payment levels based on contributions made during their prior work history. SSI provides cash assistance to people with disabilities and people aged 65 or older to ensure a minimum payment level (\$794 per month for an individual or 74% of the federal poverty level in 2021).<sup>37</sup> Whereas SSDI payments can be well above this level, low-wage people receiving SSDI also can receive SSI up to this payment level, which creates a minimum payment level, yet one that ensures that they live in poverty. Navigating these disability benefits is complex, and many people have difficulties with Social Security offices, which sometimes threaten to terminate benefits. Legal services, including those covered by the Ryan White HIV/AIDS Program, are critical for some individuals to maintain and navigate Social Security disability benefits programs. Like Social Security, Medicare is complex and raises its own challenges. People often are not familiar with how Medicare operates. This is the case for many older people who are enrolling or are enrolled in Medicare, despite having benefits counselors who support them. Understanding and navigating Medicare benefits is particularly challenging for people aging with HIV who may have to deal with high costs of HIV medications and other treatments for comorbidities. The

Access, Care, and Engagement Technical Assistance (ACE TA) Center of the Ryan White HIV/AIDS Program already exists to assist people living with HIV in accessing and using Medicare or other health coverage, as well as to provide training for service providers. Additional efforts to expand navigation services for public benefits may be needed.

## 5

### **Promote the meaningful participation of older people living with HIV in the Ending the HIV Epidemic (EHE) Initiative and in broader advocacy efforts.**

Older people living with HIV must be meaningfully engaged in the Ending the HIV Epidemic (EHE) Initiative and in responding to the issues that are important to them. Their voices matter and need to be bolstered now and in the future. Not only do older people living with HIV bring knowledge of their own needs that is critical to informing and implementing the EHE Initiative, but their experience dealing with stigma and advocacy has shaped the system of HIV services delivery and will help to ensure that the system continues to evolve. It is important to create opportunities for older people living with HIV to define their own policy agenda and inform how services are delivered for them.

People aging with HIV should be involved in all aspects of HIV programs and services, including as senior leadership, clinical staff, community health workers, and peer educators. In particular, more must be done to ensure older people living with HIV who are gay and bisexual men of color, transgender people of color, and women of color are fully involved in the HIV response. Additionally, older people living with HIV should be fully involved in responding to COVID-19—which places older people at higher risk for hospitalization and death

and disproportionately affects many communities that are most heavily impacted by HIV—as well as other health concerns that they have, such as viral hepatitis, sexually transmitted infections, substance use, and mental health. Meaningful engagement with diverse groups of older people living with HIV is also crucial for addressing the social and structural factors that lead to health inequities. To have an impact on HIV and other critical issues, advocacy efforts must aim to:

- **Engage government leaders on HIV and aging issues and strengthen diverse representation in HIV decision-making processes.** Older people living with HIV must be active in national, state, and local advocacy. AIDSWatch, the largest annual constituent-based national HIV advocacy event, and related events at the state and local level are opportunities for older people living with HIV to meet with their legislators and educate them about HIV and aging issues. Two critical areas to focus advocacy are calling for all states to expand Medicaid and pushing for policies to expand access to community-based long-term services and supports. In addition to engaging legislators and other government officials in a variety

of ways, older people living with HIV should consider participating in Ryan White Planning Councils to ensure they have input on setting HIV priorities and allocating funds for services based on their needs.

- **Work with people and organizations outside of the HIV field.** People aging with HIV must broaden the focus of their advocacy. Addressing issues that extend beyond HIV, such as Medicaid expansion efforts, expansion of the geriatrics workforce, financial support for community-based programs, and barriers to employment, may require building partnerships with aging groups, disabilities groups, and other advocates. Another priority issue is life planning for the rest of life, so that older people can have a future with joy, health, safety, purpose, companionship, employment, housing, and financial stability. Aging organizations already engage in a number of HIV-related activities, such as through the Administration for Community Living, which has supported projects and initiatives with HIV partners, including the AIDS Community Research Initiative of America (ACRIA).

## CONCLUSION

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The health care and social needs of people living with HIV are complex, and those needs change as people with HIV age. To be successful at ending the HIV epidemic in the United States, we must keep the needs of older people living with HIV at the center of our efforts.

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