

Better Integration Between HIV and Aging Systems is Critical

Older adults with HIV have unique needs that require focused attention

The United States has come a long way in its response to HIV. While challenges and gaps remain, we have built an HIV services system anchored by the Ryan White HIV/AIDS Program (RWHAP) that leverages public (Medicaid and Medicare) and private insurance such that people with HIV (PWH) now are just as likely to have insurance coverage as people without HIV.¹ While too many people with diagnosed HIV are not in care, those receiving RWHAP services have high viral suppression rates comparable to many other developed nations.² The majority of PWH in the United States are over age 50, but we have not done enough to prepare to meet both the clinical and social needs associated with aging HIV to support a high quality of life. In 2021, 53% of people in the United States with diagnosed HIV were aged 50 and older.³ Moreover, in that same year, 34% of people diagnosed at age 55 and older already had late-stage HIV (i.e. AIDS) when they received their first diagnosis, meaning they received a diagnosis later in the course of their illness causing greater health impacts.⁴ Early diagnosis and viral suppression are critical components of the national strategy to reduce the impact of HIV on individuals and communities. Older adults (those aged over 50), however, are often being left behind due to our health care system's lack of capacity to fully meet the needs of older PWH or to provide critical education, testing, HIV prevention and associated sexual health services.

THE MAJORITY OF PEOPLE WITH HIV IN THE U.S. ARE OVER 50

The HIV services system has accomplished a great deal, but more is needed to adapt to an aging population and to better leverage the aging services system:

1. Expanding Provider Capacity to Provide Better Care for People over 50 with HIV

There is a need to expand health care and provider capacity to conduct geriatric screenings of people aging with HIV and to expand the use of multidisciplinary care teams.

2. Providing Greater Leadership through Federal and State Health Care Programs

Federal and state health care agencies need to routinize regular specialized geriatric screenings for people with HIV, protect access to critical services including prescription medications and navigation services, and improve access to and quality of long-term services for people with HIV.

3. Embracing a Sexual Health Paradigm

The CDC should remove the upper age limit in its testing guidelines to include persons 65 and over and establish testing metrics for people 65 and over.

The CDC National Center for HIV, Viral Hepatitis, STD, and Tuberculosis Prevention (NCHHSTP) and the HRSA HIV/AIDS Bureau should adapt and tailor existing HIV and STI prevention interventions into comprehensive sexual health interventions for people over 50, including people with HIV.

4. Integrating HIV and Aging Services Can Create Synergies

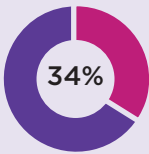
The Administration on Community Living, the Office of Infectious Disease and HIV/AIDS Policy (OIDP), Health Resources and Services Administration (HRSA) and the Centers for Medicare and Medicaid Services (CMS) should convene an interagency working group and establish priority collaborations to integrate HIV and aging programs and services.

HIV community stakeholders need to be engaged in the implementation and reauthorization of the Older Americans Act to ensure that it maximally addresses the unique concerns of people with HIV and LGBTQ people.

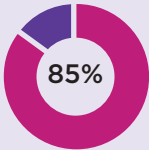
States and local jurisdictions should pass LGBTQ+ and HIV Long Term Care Bills of Rights.

HIV OUTCOMES AMONG PEOPLE WITH HIV AGE 55+

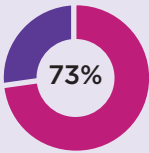
The experience of older adults with HIV is different than younger people in specific ways. Despite having the highest rate of linkages to care across all age groups, older adults have the lowest rate of rate of receiving care.



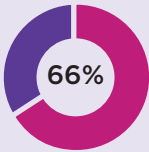
In 2021, 34% of people with HIV 55+ were diagnosed late (highest of all age groups)¹



85% were linked to care (highest of all age groups)²



73% received HIV care (lowest of all age groups)²



66% were virally suppressed (highest of all age groups)²

- Among people 55 and older, Black Americans had the highest number of new HIV diagnoses (1,241 diagnoses) and deaths (4,818 deaths) among people living with HIV compared to other races/ethnicities²
- New diagnoses among women are concentrated among older age groups, with women 55+ making up 27% of new infections (highest of all age groups)²

Sources: 1) HIV and Older People, HIV Info NIH.gov, (March 12, 2024) <https://hivinfo.nih.gov/understanding-hiv/fact-sheets/hiv-and-older-people/>. 2) National HIV/AIDS and Aging Awareness Day 2022, AIDSvu, (September 15, 2022), <https://aidsvu.org/news-updates/national-hiv-aids-and-aging-awareness-day-2022/>.

The challenge of addressing the unique clinical and psychosocial needs of people aging with HIV is complicated by our inadequate preparation and capacity to meet the needs of America's older adults more generally. The population of individuals aged 65 years or older is projected to increase by 55% by 2030.⁵ From 2000 to 2010, however, the number of geriatricians (i.e. physicians with specialty training to meet the health care needs of older people) decreased from 10,270 to 8,502,⁶ and as of 2023 there are fewer than 7,300.⁷ Moreover, funding for aging services is limited, the home care workforce has not kept pace with the need for long term services and supports that allow older adults to remain in their communities,⁸ and Medicare out-of-pocket costs and health care costs generally are unaffordable for many older adults.⁹ The challenges that confront us also offer opportunities for significant progress in four key areas:

1. EXPANDING PROVIDER CAPACITY TO PROVIDER BETTER CARE FOR PEOPLE AGING WITH HIV

As people age, PWH share many of the same health concerns as people without HIV. Due to chronic HIV, however, PWH also may experience additional health concerns. For example, they are at higher risk for developing comorbidities than people without HIV.¹⁰ Chronic immune activation and inflammation caused by HIV has been suggested as a factor for accelerated or early aging in PWH.¹¹ Additionally, long-term use of certain anti-retroviral therapies (ART) may also contribute to higher rates of comorbidities among PWH.¹² Older adults with HIV have high rates of cardiovascular and renal disease, including hypertension, diabetes and hyperlipidemia.¹³ Additionally, people aging with HIV also may be affected by hearing decline or loss, impaired oral health, premature aging of the immune system, cognitive impairment such as HIV-associated neurocognitive disorder (HAND), functional impairment such as the inability to carry out tasks needed for day-to-day living, frailty and falls, and polypharmacy (taking multiple pharmaceutical medications).¹⁴ People aging with HIV also have higher rates of substance use (tobacco, alcohol, and other drugs) compared to people aging without HIV¹⁵ and PWH are twice as likely to smoke than the national average.¹⁶ Additionally, PWH on ART can be affected by HIV-associated neuropathy (which manifests as nerve pain).¹⁷

Despite the higher rates of comorbidities among older adults with HIV, most HIV providers do not have the expertise needed to care for populations aging with HIV. At the same time, many PWH report their non-HIV providers, such as primary care providers and other specialists, lack basic knowledge about HIV. Given the comorbidities of older adults with HIV, this can mean much of an older individual's care team may be unable to treat them holistically and fail to meet their needs to ensure a high quality of life. HIV providers serving older adults may lack the time, training, and experience to address the specific needs of older adults with HIV. Common gaps in medical management of older adults with HIV include: lack of knowledge about access to affordable treatment such as hearing aids, glasses, and dental care; failure to assess functional or cognitive health; and failure to address sexual health needs.¹⁸

POLICY ACTION

There is a need to expand provider capacity to conduct geriatric screenings of people aging with HIV and to expand the use of multidisciplinary care teams.

INCORPORATING GERIATRICS INTO HIV CARE

The HIV and Aging Program at New York–Presbyterian Hospital/Weill Cornell Medical Center

was founded in 2014 to meet the needs of clients aged 50 years and older. The program has two main goals: 1) to provide integrated geriatric care within existing HIV clinic sites and 2) to provide client-driven education and program opportunities both within and outside of the clinic.

Two geriatricians offer weekly consultation. They document in the outpatient electronic health record and attend outpatient interdisciplinary rounds at the end of the day where all clients seen that day are discussed. They communicate actively with the physicians, social workers, psychiatrists, and nutritionists to identify problems and problem-solve interventions.

The program also offers **Gold Stars**, an internal social worker-driven support group that focuses on providing the space for socialization and general support while educating group participants on a variety of topics relevant to aging with HIV. In addition, the program has sponsored an arts program and links with other community-based groups to organize opportunities for clients to attend group dances and long-term survivor support groups.

Source: Harjot K. Singh et al., *From One Syndrome to Many: Incorporating Geriatric Consultation Into HIV Care*, *Clinical Infectious Diseases*, 2017;65(3):501-6.

Older adults with HIV would benefit from receiving the specialized care of a geriatrician. Due to the shortage of geriatric providers in the U.S., however, this may be unrealistic for many people. Moreover, because many older adults with HIV already see multiple specialists, adding another provider may be overwhelming. *The HIV and Aging Consensus Project*, a project sponsored by the American Academy of HIV Medicine and others recommends that providers serving older adults with HIV should: 1) prioritize and tailor care based upon a detailed assessment of their risk of morbidity and mortality, 2) identify risks which are modifiable, 3) identify the goals of the person with HIV, and 4) target interventions based upon this assessment.¹⁹ Given gaps in geriatric capacity, HIV clinics and providers should expand their use of multidisciplinary care teams and equip them with various providers with the knowledge to adequately serve older PWH, including expanding knowledge and training to appropriately screen, test, assess, and refer people aging with HIV to needed geriatric treatment and services.

It is imperative that the holistic needs of older adults impacted by HIV are addressed. Older adults impacted by HIV have needs that are not currently addressed by current medical models. Physical and mental health are determined by myriad factors and screening and linkages to services should also address:

- **Isolation and loneliness:** One study of people aged 50 years or older with HIV found the majority of participants reported loneliness and poor social support.²⁰ These dynamics can impact older people's access to treatment and services and quality of life.
- **Violence:** Older adults are vulnerable to violence, particularly in the home, but also in long-term care facilities. Older adults may experience violence from a partner, family member, community member, or a caregiver. Older LGBTQ+ adults, particularly those who are transgender, are especially vulnerable to violence.
- **Economic and housing security:** Older individuals face financial insecurity due to the low level of support they receive from social security, federal disability and local benefits systems. This can lead to insecurities in housing, food and other basic needs.
- **Support for living a healthy and active lifestyle (exercise, nutrition/dietary support):** While people who are aging, and particularly those aging with HIV are more likely to have multiple comorbidities, supporting a healthy and active lifestyle through exercise and nutrition may improve health outcomes.

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- **For those who are able and want to return to work, resources should be made available:** Many people who are aging with HIV are on disability and can no longer work, but for those interested in returning to work, opportunities should be made available.

Older adults deserve to feel safe and that they belong and are able to live the best life they are able to. A holistic person-centered approach for older adults impacted by HIV must incorporate economic, social, emotional, physiological needs, and quality of life. Providers serving older adults must recognize these critical components of health and wellbeing, and conduct screening and linkages to appropriate services.

2. PROVIDE GREATER LEADERSHIP THROUGH FEDERAL AND STATE HEALTH CARE PROGRAMS

The RWHAP, Medicaid, and Medicare all have a role to play in shaping treatment and prevention services for older adults. While there are tested models of care for older adults, these models have not been integrated into the care for older adults with and vulnerable to HIV. To meet the needs of older adults with HIV we must effectively combine geriatric and palliative care with HIV services. Additionally, HIV prevention services models also must incorporate geriatric models to effectively service the prevention needs of older adults.

The RWHAP reports the highest viral suppression rates of any health care payer/program. For PWH over the age of 50, this is no exception, with 92.9% of recipients being virally suppressed.²¹ Of more than half a million clients served by the RWHAP, 48.2% are people aged 50 years and older.²² Older adults with HIV, however, face many health challenges beyond viral suppression. Official federal recommendations for the care of older adults with HIV have yet to emerge, yet there are steps that RWHAP can take to improve the quality of care and monitoring for this population. In 2020, HRSA released two reference guides²³ describing the health challenges faced by people aging with HIV, gaps in medical management, recommendations for geriatric screenings for older PWH, as well as information on developing a care team to best serve people aging with HIV. Additionally, HRSA convened a Technical Expert Panel in November 2020 with considerations for providing medical, psychosocial and support services for older adults with HIV, opportunities for improving health care services, and how RWHAP recipients

can improve services.²⁴ To improve services, experts suggested that RWHAP recipients and subrecipients utilize planning councils and advisory committees to increase the participation in and impact of older adults in decision making. In addition to planning council and committee participation, older adults with HIV can be incorporated into health care teams as peers. Experts also suggested recipients should conduct assessments to determine needs across their jurisdictions and assess HIV provider knowledge of aging issues and geriatrician knowledge of HIV. Additionally, experts suggested that RWHAP recipients track care and services delivery for older adults. While these recommendations provide a necessary foundation of practices for the provision of services for older adults with HIV, more should be done to ensure RWHAP recipients are providing adequate care.

POLICY ACTION

Federal health care agencies should routinize regular geriatric screenings for people with HIV, protect access to critical services including prescription medications and navigation services, and improve access to and quality of long-term services for people with HIV.

RWHAP should require recipients to adopt models on aging care, including geriatric screenings for people aging with HIV, as well as mandate monitoring and evaluation metrics regarding the health and quality of life of older adults with HIV within RWHAP clinics to understand whether the needs of this population are being met.

Primary care providers and specialists serving older populations with HIV may require training and technical assistance to assess needs and integrate geriatric principles into HIV care. Incorporating geriatric care models will require organization assessments to evaluate staffing and the capacity of the health care team to provide geriatric care and services. Nurses and medical assistants, pharmacists, behavioral health providers, social workers, peer workers, and medical case managers will all need to work together to effectively provide services to people aging with HIV. These health care team members should receive training on geriatric care models including assessments and linkages to appropriate services.

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POLICY ACTION

AIDS Education and Training Centers (AETCs) should provide technical assistance to primary care providers and specialists serving older adults with HIV.

The AIDS Education and Training Centers (AETCs), a component of the RWHAP, are a national network of leading HIV experts who provide locally based, tailored education, clinical consultation and technical assistance to health care professionals and health care organizations to integrate up-to-date scientifically based comprehensive care for people living with or affected by HIV. The National Coordinating Resource Center offers e-courses and their website has various resources covering treatment and services for serving older adults with HIV. AETCs are a valuable resource for providers and should assist their efforts to serve older adults with HIV.

POLICY ACTION

CMS should provide training and technical assistance to providers for them to better integrate navigators into their clinics.

The CMS 2024 Medicare Physician Fee Schedule includes coding and payment for principal illness navigation services, including for HIV.²⁵ This updated fee schedule will allow providers serving older adults with HIV to incorporate patient and peer navigators into health care teams to better serve the physical, psychosocial, and sexual health of older adults with HIV. Patient and peer navigators are a critical component of health care and social support services and have the potential to improve services for people aging with HIV. Technical assistance will be needed to ensure services are meeting the needs of older adults with HIV.

POLICY ACTION

Provide Open and Unrestricted Access to HIV Treatment Regimens

Ensuring open access to HIV medications for older adults with HIV is an essential component of HIV aging policy because choosing an effective HIV treatment regimen is a complex decision that should be made by providers in consultation with their patients. At the federal level, the Six Protected Classes (6PC) policy in Medicare Part D requires health plans to ensure Part D enrollees have access to all, or substantially all, FDA approved antiretroviral medications without insurance barriers like prior authorizations or step therapy. This essential policy helped to ensure that Medicare beneficiaries have

unrestricted access to the best HIV treatment regimens for their clinical care and personal needs. At the state level, some states may establish statutory or regulatory access protections for HIV medicines in Medicaid, which helps to ensure that Medicaid beneficiaries aging with HIV are able to easily access the most appropriate treatment regimens for their needs.

State Health Insurance Assistance Programs (SHIPs) should coordinate with HIV service providers to ensure that participants enrolled in both Medicare and the RWHAP have access to the full scope of their benefits. It is also important that older adults with coverage through Medicaid or employer insurance have access to HIV treatment and prevention regimens without insurer-imposed barriers. For example, some states have statutory protections for ART medications in their Medicaid programs.

In 2023, CMS issued a proposed National Coverage Determination (NCD) that is anticipated to be finalized in 2024 and will transfer all Medicare coverage of PrEP from Part D to Part B. PrEP is currently covered under Medicare Part D with cost-sharing and without coverage for necessary testing and counseling. Per the proposed NCD, coverage under Part B will eliminate beneficiary cost-sharing and require coverage of seven tests and seven counseling sessions per year, aligning Medicare with the Affordable Care Act's preventative services mandate.

3. EMBRACING A SEXUAL HEALTH PARADIGM

There is a common misconception that older adults are not sexually active and are not interested in sex.²⁶ This may be compounded by health care provider discomfort with having discussions about sexual health and their own knowledge gaps regarding sexual health with people of any age, but especially among older adults. In a 2021 national study of Americans aged 65-80, 51% of men and 31% of women reported being sexually active.²⁷ Among older adults who were sexually active, respondents had lower ratings of satisfaction with their sex life and higher ratings of interest in sex.²⁸ In the same study, researchers found that only 17% of adults aged 65 to 80 reported speaking to their health care provider about sexual health in the past two years, and of those, 60% initiated the conversation.²⁹ HIV and STI testing for older adults is low and decreases with age; one third of adults aged 45-64 years have been tested for HIV, 17% of those aged 65-74 and only 8% of those 75 and older.³⁰ These realities can have stark consequences. STI incidence among people aged 65 and older more than doubled between 2000 and 2022.³¹ Providers serving older adults are not unique in their inadequate training and knowledge gaps regarding sexual health. Older adults may not be aware that they are at risk for HIV,

Older adults have the right to culturally competent care, regardless of sexual orientation or gender identity. HIV and aging models must incorporate best practices in transgender health care.

but deploying tools utilized by HIV and primary care providers to older adults can help ensure unaddressed sexual health needs among older adults are met.

POLICY ACTION

The CDC should remove the upper age limit of its testing guidelines to include persons 65 and over and establish testing metrics for people 65 and over.

Awareness of HIV status is essential to HIV prevention and treatment. However, many older adults' providers do not recommend testing and prevention services. The CDC recommends HIV testing for people between the ages of 13 and 64 as part of routine health care, but excludes those older than the age of 65 in their HIV testing guidelines. Thus, older adults' providers may not recommend testing and fail to offer prevention services. However, older adults more generally are not receiving adequate HIV testing and prevention services. A 2017 study found that the main barriers to testing people aged 50 years and older were providers low perceptions of risk and preconceptions about older people (for example, that they are not sexually active) that led them to not discuss sexual health with older adults.³² Some states have taken action to change testing requirements for older residents. In 2016, New York state removed the upper age limit for recommended HIV testing, highlighting the importance of testing across all age groups.³³

POLICY ACTION

The CDC National for HIV, Viral Hepatitis, STD, Tuberculosis Prevention (NCHHSTP) and the HRSA HIV/AIDS Bureau (HAB) should adapt and tailor existing HIV and STI prevention interventions into comprehensive sexual health interventions for people over 50, including people with HIV.

In addition to adapting HIV and STI prevention interventions and removing age limits of HIV testing, older adults must have access to PrEP, PEP and other prevention interventions. This requires provider training and health care capacity building for older adults vulnerable to HIV. PrEP medications are currently covered under Medicare Part D with cost-sharing and deductibles and under a new proposed NCD currently in early implementation, it will be covered under Part B without cost-sharing.

Older adults have the right to culturally competent care, regardless of sexual orientation or gender identity. HIV and aging models must incorporate best practices in transgender health care.³⁴ Transgender older adults face challenges in health and health care access, employment, housing and other areas. Many older transgender adults delay seeking care and services due to stigma and discrimination. This may manifest as a lack of appropriate cultural and clinical competence among providers, discomfort experienced by older transgender people regarding physical exams and conversations about their bodies, and the fear and experience of bias and discrimination with insurance and the provision of care.³⁵

4. INTEGRATING HIV AND AGING SERVICES CAN CREATE SYNERGIES

Many older PWH were leaders in early HIV advocacy efforts to ensure federal and state resources were directed to the HIV crisis and to building systems of care. Those efforts were critical to our progress. As this cohort ages, they face unique challenges that highlight the need for a more integrated approach to aging and HIV care. Currently, aging services often lack specialized support needed for older adults with HIV, leading to gaps in care and support. To address these challenges effectively, collaboration between the aging network and HIV community is essential.

POLICY ACTION

The Administration on Community Living, the Office of Infectious Disease and HIV/AIDS Policy (OIDP), Human Resources and Services Administration (HRSA) and the Centers for Medicare and Medicaid Services should convene an interagency working group and establish priority collaborations to integrate HIV and aging programs and services.

By convening a cohort of interagency representatives and older adults with HIV and combining expertise and resources, these two communities can develop comprehensive care models that address both the physical and psychosocial aspects of aging with HIV. This collaboration can lead to the creation of specialized training programs for health care providers, development of tailored policies that ensure equitable access to care, and the establishment of integrated community-based support systems. By leveraging the strengths of both the aging network and the HIV

community, we can ensure that all older Americans, including those with HIV, receive the high-quality, coordinated care and prevention services they need.

POLICY ACTION

HIV community stakeholders must engage in the implementation and reauthorization of the Older Americans Act to ensure that it maximally addresses the unique concerns of older adults with HIV and the LGBTQ+ community

The Older Americans Act (OAA) was passed in 1965 to ensure that older people across the country have the assistance, tools, and ability to age in place and in their communities, without having to enter a long-term care facility. Core OAA services include congregate and home-delivered nutrition assistance programs such as meals on wheels, seniors centers, transportation assistance such as Access-A-Ride, information, counseling and referral for long term services and supports, and legal assistance (among other programs). To plan and deliver these services the OAA funds a national aging network made up of state and local units of government, community-based organizations, and local services providers. In accordance with long-standing statutory interpretation, the Administration on Community Living (ACL) has defined LGBTQ+ older people and older PWH as populations of greatest social need in its 2024 final rule implementing the OAA³⁶ Per the OAA, grantees are required to perform outreach to greatest

social need populations and collect data on their needs. Service providers must specify how they will satisfy the service needs of LGBTQ+ and older PWH. There is great opportunity for the aging network and HIV service network (including RWHAP recipients) to partner together to best support older adults living with HIV and advance independence, well-being, and community living.

POLICY ACTION

States and local jurisdictions should pass LGBTQ+ and HIV Long Term Care Bills of Rights

Older adults face stigma and discrimination in health care settings and particularly in long-term care settings. One study found that among older LGBTQ+ adults, 43% reported mistreatment including verbal or physical abuse from other residents, refused admission/re-admission and discharge, and other types of mistreatment.³⁷ People aging with HIV are also subjected to discrimination and stigma while in facilities and when trying to gain admission. To address this, some jurisdictions and states have passed LGBTQ+ and HIV Long-Term Care Bill of Rights that protects people from discrimination on the basis of sexual orientation, gender identity (SOGI) and HIV status in long-term care settings.³⁸ These Bill of Rights may make it illegal to deny admission based on identity or HIV status, or to refuse to acknowledge and or treat a resident according to their gender identity.

THE TIME IS NOW

The field of aging needs greater push from community and advocacy stakeholders in HIV. This will require a coordinated community response, with the larger HIV community focusing greater attention on older populations impacted by HIV. HIV advocates must engage with stakeholders in the aging network along with organizations that focus on particular communities, such as diabetes, cardiovascular disease, and others. Organizations funded through the Older Americans Act and Administration on Community Living provide avenues for such engagement, and the opportunity for meaningful partnership is great.

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