40 ANNIVERSARY OF THE DENVER PRINCIPLES

FROM PATIENT RIGHTS TO HUMAN RIGHTS

CONGRESSIONAL POLICY PAPER ON

HIV AND AGING

RAYBURN HOUSE BUILDING
WASHINGTON, DC
JUNE 14, 2023 | UPDATED AUGUST 30, 2023

GILEAD

ROC 4 Aging+
EMBRACING THE PROMISE

THE DENVER PRINCIPLES

STATEMENT FROM THE ADVISORY COMMITTEE OF PEOPLE WITH AIDS (1983)
We condemn attempts to label us as 'victims,' a term which implies defeat, and we are only occasionally 'patients,' a term which implies passivity, helplessness, and dependence upon the care of others. We are 'People With AIDS.'

RECOMMENDATIONS FOR ALL PEOPLE

1. Support & Membership in our struggle against those who would fire us from our jobs, evict us from our homes, refuse to touch us, or separate us from our loved ones, our community, or our peers since available evidence does not support the view that AIDS can be spread by casual, social contact.
2. Do not scapegoat people with AIDS, blame us for the epidemic, or generalize about our lifestyles.

RECOMMENDATIONS FOR PEOPLE WITH AIDS

1. Form caucuses to choose their own representatives, deal with the media, choose their own agenda, and plan their own strategies.
2. Be involved at every level of decision-making and specifically serve on the board of directors of provider organizations.
3. Be included in all AIDS forums with equal credibility as other participants, to share their own experiences and knowledge.
4. Substitute low-risk sexual behaviors for those which could endanger themselves or their partners; we feel that people with AIDS have an ethical responsibility to inform their potential partners of their health status.

RIGHTS OF PEOPLE WITH AIDS

1. To live as full and satisfying sexual and emotional lives as anyone else.
2. To receive quality medical treatment and quality social service provision without discrimination of any form, including sexual orientation, gender, diagnosis, economic status, or race.
3. To obtain full explanations of all medical procedures and risks, to choose or refuse their treatment modalities, to refuse to participate in research without jeopardizing their treatment and to make informed decisions about their lives.
4. To ensure privacy and confidentiality of medical records, to receive human respect, and the right to choose who their significant others are.
5. To die--and to LIVE--in dignity.

RECOMMENDATIONS FOR HEALTHCARE PROFESSIONALS

1. Come out, especially to their patients who have AIDS.
2. Always clearly identify and discuss the theory they favor as to the cause of AIDS since this bias affects the treatments and advice they give.
3. Get in touch with their feelings (e.g., fears, anxieties, hopes, etc.) about AIDS and not simply deal with AIDS intellectually.
4. Take a thorough personal inventory and identify and examine their own agendas around AIDS.
5. Treat people with AIDS as a whole people and address psychological issues as well as biophysical ones.
6. Address the question of sexuality in people with AIDS specifically, sensitively and with information about gay male sexuality in general, and the sexuality of people with AIDS.

Dedication

This policy paper honors the courageous efforts of a group of men living with AIDS who created The Denver Principles and gave voice to people with AIDS in the early days of the AIDS epidemic, when they were routinely ostracized, feared, and reviled, subject to rejection by their families and friends, loss of employment and housing, and faced tremendous difficulties accessing healthcare for a mysterious illness that was believed to be 100% fatal. This paper also honors the history and future of people over 50 aging with HIV.

About this Policy Paper

This policy paper provides information about people who are aging with HIV.

There are three main groups of individuals who are aging with HIV: older adults living with HIV, long-term survivors, and lifetime survivors. Below are some examples of organizations/entities that focus on each group:

1. **Gilead's HIV Age Positively Initiative:** This initiative specifically supports older adults living with HIV who are over 50 years old. Its goals are to improve care coordination, provide more resources for better well-being, and advocate for policy changes that benefit older adults living with HIV.
2. **The Reunion Project:** This project uses the term "long-term HIV survivors" to describe people who have been living with HIV for a significant period of time. This includes individuals who have been living with HIV since the early days of the epidemic, young adults who acquired HIV from their mother, people who have been living with HIV for shorter periods, and HIV-negative caregivers and family members who have experienced the impact of HIV. Each survivor group has unique needs and experiences complex trauma due to the loss and pain caused by HIV.
3. **The Dandelions:** This group of lifetime survivors advocates for the use of the term "lifetime survivors" instead of "people who vertically acquired HIV" when referring to young individuals who have been living with HIV since birth. The Dandelions aim to educate and support themselves and others facing the unique challenges of being lifetime survivors, such as advanced disease resulting from a weakened immune system (immunosuppression), neurocognitive delay and dysfunction, delayed puberty, short stature, and changes in body fat distribution (lipodystrophy).

These organizations and initiatives among a host of others focus on addressing the specific needs and challenges faced by people aging with HIV.

This policy paper focuses on older adults living with HIV.

Ribbon Organizing Center for the HIV Age Positively Initiative (ROC4Aging+) under the leadership of the Policy Action Group in partnership with the U.S. People Living with HIV Caucus and key community stakeholders created this document. This document summarizes a more extensive policy paper that will be released electronically on June 30, 2023.

EXECUTIVE SUMMARY

Congressional Policy Paper on HIV and Aging

Forty years ago, aging issues were not considered.

Forty years ago, people diagnosed with AIDS typically died within a few months of diagnosis, some within days or weeks, and a few survived a year or longer. Aging issues were not considered; immediate, short-term survival was the priority. With the advent of effective combination antiretroviral therapy in the mid-1990s, what it meant to be diagnosed with HIV changed dramatically. Instead of an almost-certain death sentence, people living with HIV increasingly survived and thrived. The prognosis changed so dramatically that within a few years, a person diagnosed with HIV, with healthcare access and economic and housing security, had every reason to expect to live a normal lifespan. Another benefit of combination antiretroviral therapy is when people living with HIV take their medication as prescribed and consistently maintain an undetectable viral load (the level of HIV in their blood is so low that standard laboratory tests cannot detect it), they cannot transmit the virus to their sexual partners. This concept is known as Undetectable equals Untransmittable, or U=U, which has been proven in numerous scientific studies, including the landmark PARTNER and HPTN 052 studies. These studies confirmed that maintaining an undetectable viral load eliminates the risk of sexually transmitting HIV to others. U=U is a powerful message and concept for older people living with HIV as it improves their quality of life by improving health, eliminating the fear of transmitting HIV to others, and erasing HIV-related stigma.

By 2030, 70% of people living with HIV will be 50 and over.

Long-term survivorship was made possible by the collective actions of people, who, as advocates and activists, fought for effective care, treatment, supportive services, systematic and structural change, and the efforts and success of researchers, healthcare and human service providers, and caregivers. Yet, a paradigm shift is needed to ensure the continued survivability of people currently aging with HIV and for future generations of people who may be diagnosed with or acquire HIV.

New, creative, and evidence-informed efforts on how we plan for the care, treatment, and essential supportive services for people living with HIV over 50 years and older, as well as people living with HIV over 65 years, who may suffer a higher level of comorbidities and infirmities are needed.

Why? With the advent of effective care, treatment, and support, once a person is diagnosed with HIV, they will need life-long care and treatment. However, HIV-related stigma, discrimination, and structural conditions -- including racism, homophobia, sexism, transphobia, xenophobia, ableism, and poverty – continue to create barriers to access to and quality of care for older adults living with HIV.

Therefore:

- Organizations should train staff on ageism, aging, and supporting individuals with HIV as they age. They should also familiarize themselves with eldercare and gerontology services to facilitate referrals for eligible individuals living and aging with HIV.
- Organizations must commit to ensuring that, at the very least, staff participate in training on aging with HIV, ageism, and ableism.
- Providers should not assume that patients fully understand or can effectively communicate the physical and cognitive changes and reduced quality of life associated with aging. Instead, healthcare systems must ensure that resources and information about aging are readily accessible to individuals.
- Ensure older clients and patients are aware of available support services to address loneliness, isolation, and other psychosocial needs. This includes addressing mental health disorders, complex trauma, and post-traumatic stress disorder (PTSD) stemming from past and present traumatic experiences, as well as the additional trauma associated with aging with an HIV diagnosis.
- Provide older clients/patients information and support resources so they can discover what it means for them to age with HIV graciously.
- Address poverty and social isolation and the lack of access for people living and aging with HIV to information, support services, and resources needed for well-informed decisions about employment and optimal healthy, self-directed transitions to or from employment or changing jobs and career development.
- The federal HIV response must strengthen concrete commitments, strategies, and structural interventions to improve the quality of life for people living with HIV.

This is a Congressional Call to Action

Support HIV Appropriations for Healthcare Services

Fund the Ryan White HIV/AIDS Program at a minimum of $3.085 billion, consistent with the request of the AIDS Budget and Appropriations Coalition of the Federal AIDS Policy Partnership. We additionally urge Congress to fund HIV/AIDS research at $3.673 billion and include unfunded research priorities that address the relationship between HIV and aging.

Fund Programs and Models of Care for Older Adults Living with HIV

Pass legislation that appropriates designated funding to develop new and support existing programs and models of care (e.g., centers of excellence for people aging with HIV) that provide comprehensive health care for older adults living with HIV that weave together HIV care, chronic disease management, and geriatric assessment and care. Federal agencies responding to the issue must coordinate opportunities for care and support. We call for funding clinics that specialize in HIV and aging and are scaled up at a level where all people with HIV have access to services.

Fund Biomedical and Implementation Research

Increasing National Institutes of Health (NIH) funding is critical to address research priorities related to HIV and aging. Many research questions need answers. We need to understand how chronic inflammation due to the HIV reservoirs in the body refers to the early and multiple comorbidities, HIV drug resistance, the need to discover new viral targets and new HIV drugs, and the inclusion of HIV 65+ in HIV research.

Prioritize Older Adults Living with HIV in Public Health Responses

Provide funding that supports the efforts of the End the HIV Epidemic Initiative and the National HIV/AIDS Strategy that ensures that older adults living with HIV are prioritized in public health responses for 1) ending the HIV epidemic and 2) addressing infectious disease outbreaks and epidemics.

Build the Capacity of the Healthcare Workforce to Better Serve Older Adults Living with HIV

Pass legislation that incentivizes the development and implementation of programs to increase the capacity of health care and social services workforces to address HIV and aging and increase cultural sensitivity, competency, and humility among these workforces. Additionally, provide capacity building to HIV providers to increase understanding and utilization of the Older Americans Act (OAA) available resources for their clients.

Fully Fund General Elder and Gerontology Services and Programs

Commonly observed clinical characteristics of older adults without HIV are seen earlier in older adults with HIV. In addition, to accelerate aging, people living with HIV are experiencing multiple comorbidities earlier in their life cycle. Hence the need for geriatric assessments which provide a complete view of a patient's function, cognition, and health and improve prognostication and treatment decisions.

Develop Access to Information, Services, and Resources People Living with HIV Need to Consider and Participate in Self-Determined Employment

Fund culturally responsive and informed employment services initiatives to expand opportunities for self-determined employment decisions and transitions for people living with HIV that maintain or improve access to healthcare, medical treatments, housing, and economic security.

Review Eligibility Requirements for Federal Benefit Programs

Review and revise the eligibility thresholds for long-term survivors to access federal programs. Research demonstrates that people living with HIV experience an accelerated aging process. However, the laws that govern the age requirements for social security or retirement annuities were written in the early 1950s, long before we had all the information on accelerated aging.

Review Eligibility Requirements for Federal Benefit Programs

Review and revise the eligibility thresholds for long-term survivors to access federal programs. Research demonstrates that people living with HIV experience an accelerated aging process. However, the laws that govern the age requirements for social security or retirement annuities were written in the early 1950s, long before we had all the information on accelerated aging.

Pass Legislation to End HIV Criminalization

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

Fund Initiatives for Structural Change that Improve the Lives of People Living with HIV
Demanding Better: An HIV Federal Policy Agenda by People Living with HIV includes recommendations for Congress to meaningfully improve the lives of people living with HIV. These recommendations range from legislation already introduced, such as the SAFE Sex Worker Study, HEAL for Immigrant Families, and American Dream and Promise Acts, to new legislation and change to existing policies. These recommendations cover a range of issues that impact every aspect of the lives of people living with HIV, from housing to food and economic security.

Congressional Policy Paper on HIV and Aging

This policy paper is an acknowledgment of the courageous efforts of a group of men living with AIDS who created The Denver Principles and gave voice to people with AIDS in the early days of the AIDS epidemic, when they were routinely ostracized, feared, and reviled, subject to rejection by their families and friends, loss of employment and housing, and faced tremendous difficulties accessing healthcare for a mysterious illness that was believed to be 100% fatal. This Brief also honors the history and future of people over 50 aging with HIV. It acknowledges intersections of race, gender, geography, and class as they impact access and outcomes for people living with HIV.

SECTION 1: Rationale and Background Information

Forty years ago, people diagnosed with AIDS typically died within a few months of diagnosis, some within days or weeks, and a few survived a year or longer. Aging issues were not considered; immediate, short-term survival was the priority. With the advent of effective combination antiretroviral therapy in the mid-1990s, what it meant to be diagnosed with HIV changed dramatically. Instead of an almost-certain death sentence, people living with HIV increasingly survived and thrived. The prognosis changed so dramatically that within a few years, a person diagnosed with HIV, with healthcare access and economic and housing security, had every reason to expect to live a normal lifespan. Another benefit of combination antiretroviral therapy is that people living with HIV take their medication as prescribed and consistently maintain an undetectable viral load. This concept is known as Undetectable equals Untransmutable or U=U. Studies produced definitive evidence that maintaining an undetectable viral load eliminates the risk of sexually transmitting HIV to others. U=U is a powerful message and concept for older people living with HIV as it improves their quality of life by improving health, eliminating the fear of transmitting HIV to others, and erasing HIV-related stigma.

Long-term survivorship was made possible by the collective actions of people who, as advocates and activists, fought for effective care, treatment, supportive services, and structural change, as well as the efforts and success of researchers, health care and human service providers, human service providers, and caregivers. By 2021, the CDC estimated that the majority of people living with HIV and AIDS in the U.S. were over 50 years old, and it is predicted that 70% of people living with HIV will be over 50 by 2023 (https://acl.gov/news-and-events/acl-blog/older-adults-hivaids-growing-population).

In the U.S., there are approximately 12,310 persons with vertically (or perinatal) acquired HIV (https://www.cdc.gov/hiv/library/reports/hiv-surveillance/vol-31/content/children.html.) In local jurisdictions, it has been estimated that by 2030, in some individual jurisdictions such as New York City, over 80% of people living with HIV may be older than 50 as well (https://www.nyc.gov/assets/doh/downloads/pdf/dires/hiv-surveillance-annualreport-2021.pdf)

People aging with HIV represent a broader, diverse community of survivors who share a common thread of pain, loss, stigma, and unresolved trauma experienced in various degrees and at different times throughout the epidemic.

With this longer life expectancy, people with long-term HIV exhibit many clinical characteristics commonly observed in aging, such as multiple chronic diseases or conditions, the use of multiple medications (polypharmacy), changes and declines in physical and cognitive abilities and functioning, social isolation, and increased vulnerability to stressors (frailty), and drug use and addiction.

As survivors with HIV grow older, they may experience an array of "unintended consequences of HIV survival (Sharp and Berry, 2016); (https://www.tpan.com/sites/default/files/TRP%20Roundtable%20Report%20-%20Creating%20a%20Framework%20for%20HIV%20Survival%20FINAL.pdf) such as:

- Premature (or accelerated and accentuated) aging due to ongoing immune activation.
- Psychosocial issues include mental health disorders, depression, anxiety, complex trauma, cognitive decline, social isolation, and post-traumatic stress disorder (PTSD) resulting from past and present lived traumatic experiences, but aging with an HIV diagnosis can be equally traumatic in itself.
- Ageism is a type of prejudice perpetuating the social invisibility of older adults, perhaps more acutely in those with HIV.
- Ableism is a type of discrimination that favors non-disabled or able-bodied people.
- Economic insecurity (e.g., poverty).
- Social isolation.

Combined with these unintended consequences, internalized HIV stigma was positively linked to the severity and course of PTSD symptoms. Research indicates unresolved trauma is a significant factor in treatment non-adherence (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7466667/.) Furthermore, a comparable problem is an HIV-related disability resulting from physical and mental health symptoms or impairment, or difficulty completing activities of daily living that have been directly linked to challenges in maintaining social inclusion (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6615082/.) Lifetime trauma and discrimination increase the risk of heart disease and physical and cognitive decline (https://www.ahajournals.org/doi/10.1161/HCQ.0000000000000110.)

There is a need for a paradigm shift in how we plan for the care, treatment, and essential supportive services for people living with HIV over 50 years and older, as well as the needs of people living with HIV over 65 years and older who may suffer a higher level of comorbidities and infirmities. New evidence-informed efforts are needed to improve the health and quality of life of people aging with HIV.

Why? With the advent of effective care, treatment, and support, once a person is diagnosed with HIV, they will need life-long care and treatment. However, HIV-related stigma, discrimination, and structural conditions -- including racism, homophobia, sexism, transphobia, xenophobia, ableism, and poverty – continue to create barriers to access to and quality of care for older adults living with HIV. Therefore:

- Organizations must commit to training staff on ageism, aging, and how to effectively HIV organizations, providers, and other support systems should become familiar with the vast array of general and community elder and gerontology services and programs to facilitate linkages and referrals for eligible persons living and aging with HIV.
- Organizations must commit to ensuring that, at the very least, staff participates in training on aging with HIV, ageism, and ableism.
- Providers cannot assume patients fully understand or can articulate the physical and cognitive changes and reduced qualities of life experienced. Healthcare systems must make resources and information about aging easily accessible.

- Make sure older clients/patients are aware of the support services available to help combat loneliness and isolation, and other psychosocial needs, including mental health disorders, complex trauma, and post-traumatic stress disorder (PTSD) resulting from past and present lived traumatic experiences, in addition to experiencing trauma as a result of aging with an HIV diagnosis.
- Provide older clients/patients information and support resources so they can discover what it means for them to age with HIV graciously.
- In fighting poverty and social isolation, address the lack of access for people living and aging with HIV to information, support services, and resources needed for well-informed decisions about employment and optimal healthy, self-directed transitions to or from employment or changing jobs and career development.
- The Federal HIV Response must strengthen concrete commitments, strategies, and structural interventions to improve the quality of life for people living with HIV.

SECTION 2: HIV and Aging Policy Agenda

In 1983, The Denver Principles were written to empower people living with HIV to participate in the policy development and decision-making that so profoundly affected their lives and to guide healthcare providers and caregivers on treating PLHIV as whole persons with the right to be partners in decision-making processes. The principles created a space for people with HIV to regain meaningful control after being treated as passive participants as HIV took their health and lives.

It also became a strong manifestation of the principle of "nothing about us, without us," demanding full participation of groups affected by that policy to this day. We return to these principles on their 40th anniversary to continue the work initiated by The Denver Principles to meet the changing needs of people living with HIV, especially those over 50 years old.

CONGRESS must:

•Support HIV Appropriations for Healthcare Services.
Fund the Ryan White HIV/AIDS Program at a minimum of $2.942 billion, consistent with the request of the AIDS Budget and Appropriations Coalition of the Federal AIDS Policy Partnership. We additionally urge Congress to fund HIV/AIDS research at $3.673 billion and include unfunded research priorities that address the relationship between HIV and aging.

•Review Eligibility Requirements for Federal Benefit Programs.
Review and revise the eligibility thresholds for long-term survivors to access federal programs. Research has shown that for people living with HIV, they experience an accelerated aging process. However, the laws that govern the age requirements for Social Security or retirement annuities were written in the early 1950s, long before we had all the information we now have on premature aging.

•Fund Programs and Models of Care for Older Adults Living with HIV.
Pass legislation that appropriates designated funding to develop new and support existing programs and models of care, e.g., centers of excellence for people aging with HIV that provide comprehensive health care for older adults living with HIV that weave together HIV care, chronic disease management, and geriatric assessment and care. Federal agencies responding to the issue must coordinate opportunities for care and support. We call for funding clinics that specialize in HIV and Aging and that are scaled up at a level where all people aging with HIV have access to services.

•Fund Biomedical and Implementation Research.
Increasing NIH funding is critical to address research priorities related to HIV and aging. Many research questions need answers. We need to understand how chronic inflammation due to the HIV reservoirs in the body refers to the early and multiple comorbidities, HIV drug resistance, the need to discover new viral targets and new HIV drugs, and the inclusion of people aging with HIV over 65 older in HIV research.

•Prioritize Older Adults Living with HIV in Public Health Responses.
Provide funding that supports the efforts of the End the HIV Epidemic Initiative and the National HIV/AIDS Strategy that ensures that older adults living with HIV are prioritized in public health responses for 1) ending the HIV epidemic and 2) addressing infectious disease outbreaks and epidemics.

•Build the Capacity of the Healthcare Workforce to Better Serve Older Adults Living with HIV.
Pass legislation that incentivizes the development and implementation of programs to increase the capacity of health care and social services workforces to address HIV and aging and increase cultural sensitivity, competency, and humility among these workforces. Additionally, provide capacity building to HIV providers to increase understanding and utilization of the Older Americans Act (OAA) available resources for their clients.

•Fully fund general elder and gerontology services and programs.
Commonly observed clinical characteristics in older people without HIV are seen earlier than in older adults with HIV. Another difference is that in addition to HIV, comorbidities are multiple and come early in the life span of people aging with HIV. Congress must appropriate Fiscal Year (F.Y.) 2024 funding for Older Americans Act (OAA) programs at or above $2.46 billion as authorized in the Supporting Older Americans Act of 2020.

• Develop Access to Information, Services, and Resources People Living with HIV Need to Consider and Participate in Self-Determined Employment
Fund culturally responsive and informed employment services initiatives to expand opportunities for self-determined employment decisions and transitions for people living with HIV that maintain or improve access to healthcare, medical treatments, housing, and economic security.

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

SECTION 3: Supporting Evidence

Support HIV Appropriations for HIV Healthcare Services

The Health Resources and Services Administration (HRSA) Ryan White HIV/AIDS Program (The Ryan White HIV/AIDS Program or RWHAP), with annual funding of $2.4 billion, is the most extensive HIV-specific discretionary grant program in the United States and the third largest source of federal funding for HIV care (behind Medicaid and Medicare). Since the advent of antiretroviral therapy in 1995, the AIDS epidemic has virtually turned around, yet there have been and remain several unintended consequences of this success. Ryan White serves as the payer of last resort for more than half of people living with HIV in the United States. The program strives to ensure equitable access to quality health care for many underserved people living with HIV/AIDS. Furthermore, by 2030 more than 64% of Ryan White Program clients will be 50 and older, and it is ultimately the safety net for this population.

Through its comprehensive system of HIV care, treatment, and support services, the RWHAP works to meet people with HIV where they are and addresses many disparities, i.e., economic status, ethnicity, etc. The program also seeks to provide HIV treatment and support services by educating HIV care providers to better serve clients through the implementation of innovative programs and strategies to reduce HIV disparities in populations in geographic regions most affected by the HIV epidemic. More than 73 percent of RWHAP clients are from racial/ethnic minority populations disproportionately affected by HIV and HIV disparities, including 46.6 percent Black/African American and 23.3 percent Hispanic/Latino clients. In addition, 60.7 percent of RWHAP clients live below 100 percent of the Federal Poverty Level, and 46.8 percent are aged 50 years or older.

Great progress has been made in the research, development, and approval of ARVs. Since 1995 favorable health outcomes for those able to access the new drugs dropped virus levels significantly. Over time barriers to HIV care brought the management of the epidemic in the US to the levels we see today. However, management of those on treatment remains a challenge today, as demonstrated by viral suppression rates that are lower than the overall rate of 88.1 percent for Black/African American people, transgender people, and youth. In addition, HIV disparities persist in the number of new HIV diagnoses. Older adults are more likely to be diagnosed with HIV and AIDS concurrently, linkage to care and treatment, and retention in care. Efforts to reduce HIV disparities must address health inequities related to wealth and capital as sources of inequity and injustice, lack of housing and transportation; mental health and substance use disorders; criminalization and incarceration, systemic racism, xenophobia, transphobia, queerphobia, stigma, and the geographic distribution of resources, including spatial and technological inequities, as sustainers of inequity. To further address health disparities and inequities, HRSA's RWHAP is supporting the Ending the HIV Epidemic in the U.S. Initiative by “linking people with HIV who are either newly diagnosed or are diagnosed but currently not in care to essential HIV care and support services in priority jurisdictions.”

The Policy Action Group also urges the AIDS Budget and Appropriations Coalition of the Federal AIDS Policy Partnership to specifically recognize the needs of people living with HIV and experiencing accelerated aging. Congress should specifically urge HRSA to implement prevention care and services to prevent accelerated aging in PLWH, including assistance and support around diet, exercise, physical therapy, mental health care, and lifestyle changes to encourage a healthy lifestyle that might help slow aging and onset for comorbidities.

Fund Programs and Models of Care for Older Adults Living with HIV.
General gerontology/elder care is complex and requires more time and care coordination. Care for those aging with HIV is equally, if not more, involved. People aging with HIV suffer accelerated aging -- the earlier onset of comorbidities (e.g., heart disease, kidney, bone disease, frailty, cognitive and physical function impairment) at higher rates than people without HIV. Psychosocial issues exacerbate this complexity, including isolation, poverty, lack of family support systems, and past and present trauma.

People aging with HIV suffer accelerated or premature aging - the earlier onset of comorbidities (e.g., heart disease, kidney, bone disease, frailty, cognitive and physical function impairment) at higher rates than the general population. Psychosocial issues exacerbate this complexity, including isolation, poverty, lack of family support systems, and past and present trauma. Medical provider and specialist visits are generally 15-20 minutes, so they have too little time to provide the necessary care and attention. Furthermore, HIV Clinics are understaffed and unable to provide quality care, with limits on visit length, and care coordination for an elderly or older population that faces many challenges is sorely lacking. Funding to support these programs with a focus on extended visits and care coordination is needed for Ryan White Care clinics, the primary source of HIV healthcare for older adults over 50 years old, especially for older adults living with HIV over 65 years old.

Funding is also needed to bring care for older people living with HIV in line with the new IAS-USA HIV Guidelines. These guidelines say older people living with HIV over 50 should receive elder screenings for cognitive impairment, mobility, physical function, frailty, and bone mineral density testing. So, all HIV clinics should be providing these screenings. This new standard of care is set by IAS, whose panel is made up of leading HIV researchers and clinicians. Prevention care and services are also needed to prevent accelerated or premature aging in people living with HIV, including services and support around diet, exercise, physical therapy, mental health care, and lifestyle changes encouraging a healthy lifestyle that might help slow aging and the onset of comorbidities. For people undergoing menopause, particular attention may be needed to explore healthcare needs in research, clinical care, and service delivery.

Prioritize Older Adults Living with HIV in Public Health Responses.
Ending the HIV Epidemic in the U.S. (EHE) is a bold plan announced in 2019 that aims to end the HIV epidemic in the United States by 2030 (https://www.hiv.gov/federal-response/ending-the-hiv-epidemic/overview/.) Agencies across the U.S. Department of Health and Human Services (HHS) developed an operational plan to pursue that goal accompanied by a request for additional annual funding. However, the EHE essentially does not discuss specific treatment needs for people aging with HIV.

The National HIV/AIDS Strategy (Strategy)is a five-year plan that details principles, priorities, and actions to guide the national response to the HIV epidemic (https://www.hiv.gov/federal-response/national-hiv-aids-strategy/national-hiv-aids-strategy-2022-2025/). The Strategy is now updated through 2025. The Strategy is clear that a focus must be placed on people aging with HIV. More than one-half of people diagnosed with HIV in the United States today are over 50 years old. Although an indicator of the success of modern HIV treatment, this statistic signals the need to tailor services to individuals within this population to continue their engagement in care and viral suppression and address the comorbidities and psychosocial needs often associated with aging." Additionally, Objective 2.5 of the strategy details efforts to provide care to people aging with HIV and long-term survivors. We must ensure that the full spectrum of HIV services is available to older adults living with HIV. Specifically, in addition to the services stated in this Brief, we recommend that the CDC change the (artificial) upper age limit from 13-64 years to 13 and older.

A**Build the Capacity of the Healthcare Workforce to Better Serve Older Adults Living with HIV**
In recent years, due to market forces, the changing nature of the HIV epidemic, shifts in health care, and other factors, the HIV workforce has been shrinking. A lack of expertise in HIV issues, including infectious disease, results in reductions in care and treatment for people living with HIV. A report from an extensive study by the American Academy of HIV Medicine (AAHIVM) notes that practicing providers cite "increasing non-patient care responsibilities, decreased support staff, and increasing administrative burden" as common barriers to care provision. Numerous studies suggest that low reimbursement rates and pay scales are primary deterrents for new providers, especially for students with school debt. Given the growing number of older people aging with HIV, there is a need not only for new expertise in HIV but for practitioners familiar with the impact of aging on people living with HIV as well.

One study, Strengthening the HIV Workforce, notes the need to build a pipeline for attracting and hiring new professionals, building capacity, opportunities for collaboration, and retention (https://aidsetc.org/sites/default/files/resources_files/SEAETC_Strengthening_HIV_Workforce_11022016_Final.pdf). Additionally, the HIV Medicine Association and Ryan White Medical Providers Coalition urge funding the Bio-Preparedness Workforce Pilot Program to protect public health and improve patient care. The pilot was created within the Public Health Loan Repayment Program, for which $100 million was authorized for FY24 in the Consolidated Appropriations Act of 2023 as part of the PREVENT Pandemics Act. These programs should include specific components recognizing the issue of HIV and aging as critical components in the delivery of HIV care.

Another solution to the care gaps involves expanding and strengthening the Nurse Practitioner workforce in HIV and gerontology care. Expanding full practice authority in all U.S. states and territories is central to this. Full Practice Authority is the authorization of nurse practitioners (NPs) to evaluate patients, diagnose, order, and interpret diagnostic tests, and initiate and manage treatments — including prescribing medications independently under the exclusive licensure authority of the state board of nursing (https://www.aanp.org/advocacy/advocacy-resource/policy-briefs/issues-full-practice-brief.) Unfortunately, many states with the most restrictive practice rules for APRNs and PAs also have higher HIV workforce shortages creating barriers to expert care that likely contribute to HIV health disparities.

When able to practice at the full extent of their education and licensure, nurse practitioners provide high-quality and effective HIV care, including the ability to screen, diagnose, and treat HIV and conditions of aging and provide care coordination to persons aging with HIV. Numerous studies have shown that the quality of HIV care and client satisfaction with care provided by Nurse Practitioners is at least equal to HIV physicians and, in some cases, superior to care provided by non-HIV specialist physicians (https://pubmed.ncbi.nlm.nih.gov/16287794/, https://www.sciencedirect.com/science/article/abs/pii/S1555415521003585, and https://www.npjournal.org/article/S1555-4155(13)00410-8/fulltext.) Across all healthcare, expanding the roles of Nurse Practitioners is a viable and effective part of the solution to disparities in healthcare access, most notably for people living and aging with HIV. Stakeholders are encouraged to advocate and support full practice authority for NPs and various funding programs for training and loan repayment to expand this critical part of the HIV and aging healthcare workforce.

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Pass the REPEAL Discrimination Act

HIV criminalization is the discriminatory practice of punishing people living with HIV based on their HIV status. These laws target people living with HIV for prosecution or harsher sentencing in situations where a person not living with HIV would either face no penalties or far less severe penalties. Many states and territories, encouraged by Congress, created criminal statutes based on perceived exposure to HIV, and prosecutions for such perceived exposure have occurred in at least 39 states. These penalties and prosecutions are imposed on people living with HIV, even without actual HIV transmission, and no or low risk that transmission could occur.

Many people convicted of crimes due to their HIV status or who received harsher penalties are aging with HIV and may still be subject to prison or other penalties. Additionally, with many more people 50 years old living with HIV, prosecutions of older people living with HIV may also increase.
To that end, Congress should pass the REPEAL (Repeal Existing Policies that Encourage and Allow Legal) HIV Discrimination Act. The bill would allow Administration officials to review federal and state laws and policies in consultation with people living with HIV and to make recommendations to update public policy. The bill should specifically make recommendations to ensure that people aging with HIV are not unjustly prosecuted or sentenced and can receive the care and treatment that they need in jail or prison if necessary.

Address Social and Economic Inequities Confronted by People Living and Aging with HIV

In 2020, the U.S. People Living with HIV Caucus, in collaboration with networks of people living with HIV across the country, released Demanding Better: An HIV Federal Policy Agenda by People Living with HIV (https://www.pwn-usa.org/wp-content/uploads/2021/07/Networks-Policy-Agenda-FINAL.pdf.) This policy agenda discusses the complex policies of services and programs essential to create access to stable health enclose many people living and aging with HIV in progressive, deepening poverty. The lack of response to the need for information and support for people living with HIV to consider and pursue working extends across all federal public health, workforce development, and vocational rehabilitation programs. It serves as an additional barrier to employment and economic advancement, setting up severe financial struggles and unequal physical and mental health outcomes for people living with HIV as they grow older. Access is needed to information and guidance to navigate public benefits constrictions to work activity and increasing income, with trauma-informed employment services and resources to strengthen the ability of people living with HIV to prepare for and enter living wage, healthy employment that maintains or improves access to economic, healthcare access and housing security.

RESOURCES

HIV Age Positively Initiative, Gilead Sciences, Inc.

https://www.gilead.com/purpose/partnerships-and-community/hiv-age-positively

Through their HIV Age Positively initiative, Gilead Sciences, Inc., has partnered with 23 national, regional, and local organizations to fund their program- and/or policy-related initiatives to help improve the health and quality of life of people living with HIV age 50 and older.

Ribbon Organizing Center for Aging

https://roc4aging.org/

Ribbon Organizing Center for Aging (ROC4Aging) is a national technical assistance provider for Gilead Sciences, Inc., HIV Age Positively initiative and is in the Washington, DC, Metropolitan Area (Largo, MD and Washington, DC). The purpose of the ROC4A is to support 23 HIV Age Positively grantees by providing comprehensive technical assistance to strengthen their capacity to respond to the changing social and health care needs of an aging HIV population, ensure access to high-quality HIV primary care and aging services, and advocate for public policies that will enhance the well-being, quality of life, and dignity of all persons living with HIV as they embrace the promise of a long and fulfilling life made possible by effective HIV treatments.

United States People Living with HIV Caucus

https://www.hivcaucus.org/

The United States People Living with HIV Caucus (also known as the HIV Caucus), was formed in 2010 as a national voice for people living with HIV (PLHIV). Our members are PLHIV-led groups, organizations, and networks, as well as individual advocates living with HIV. The HIV Caucus advocates for human rights and dignity for people living with HIV. We provide leadership development and technical assistance to people living with HIV & HIV service organizations. The HIV Caucus co-organizes AIDSWatch, the annual HIV advocacy event that brings together hundreds of PLHIV and allies from around the country to engage with Congress and federal agencies.

The 2022-2024 HIV Age Positively Grantee Websites

- Abounding Prosperity, Inc. (TX): https://www.aboundingprosperity.org/
- APLA Health (CA): https://aplahealth.org/
- Association of Nurses in AIDS Care (OH., DC): https://www,nursesinaidscare.org/
- Cascade AIDS Project (OR): https://www.capnw.org/
- Christie's Place (CA.): https://christiesplace.org/
- Coalition on Positive Health Empowerment (NY): https://copehealth.org/
- HealthHIV (DC): https://healthhiv.org/
- Illinois Public Health Association (IL): https://ipha.com/
- Latino Commission on AIDS (NY): https://www.latinoaids.org/
- Los Angeles LGBT Center (CA): https://lalgbtcenter.org/
- MPact: Global Action for Gay Men's Health and Rights (CA): https://mpactglobal.org/
- My Brother's Keeper, Inc. (MS): https://www.mbkinc.org/
- Prevention Access Campaign (NY): https://preventionaccess.org/
- Pride Center of Maryland (MD): https://www.pridecentermd.org/
- Professional Association of Social Workers in HIV and AIDS (AL): https://paswha.org/
- SAGE (NY): https://www.sageusa.org/
- San Francisco AIDS Foundation (CA): https://www.sfaf.org/
- Shanti Project (CA): https://www.shanti.org/
- The Reunion Project (IL): https://www.reunionproject.net/
- The TranLatin @ Coalition (CA): https://www.translatinacoalition.org/
- THRIVE SS, Inc. (GA): https://thrivess.org/
- USCF Health (CA): https://www.ucsfhealth.org/
- Us Helping Us (DC): https://www.ushelpingus.org/

Additional Resources: Websites

- AIDS United - HIV & Aging: Older Adults Living and Thriving with HIV (in English and Spanish): https://aidsunited.org/hiv-aging-older-adults-living-and-thriving-with-hiv/
- American Academy of Medicine - HIV & Aging: https://aahivm.org/hiv-and-aging/
- Diverse Elders Coalition: https://diverseelders.org/hiv-aging/
- Gilead Sciences 2021 HIV Age Positively Report: https://www.gilead.com/-/media/files/pdfs/other/GILEAD-HIV-Age-Positively-Report.pdf
- Grant Makers in Aging - HIV and Aging: https://www.giaging.org/initiatives/hiv-and-aging/
- HIV and Aging Research Consortium: https://hiv-arc.org/
- HIV.gov - HIV and Aging: https://www.hiv.gov/blog/hiv-and-aging/
- National AIDS Treatment Advocacy Project (NATAP): https://www.natap.org
- National Institute on Aging: https://www.nia.nih.gov/health/hiv-aids-and-older-adults/
- National Resources Center for Aging: https://aginghiv.org/
- NMAC: https://www.nmac.org/2020-hiv-50-strong-and-healthy-program-new-members/
- TargetHIV - Aging: https://targethiv.org/library/topics/aging-population/

Useful Resource Documents

Addressing the Health Care and Social Support Needs of People Aging with HIV

- https://ryanwhite.hrsa.gov/sites/default/files/ryanwhite/resources/hrsa-aging-tep-summary.pdf

HRSA's Ryan White HIV/AIDS Program Optimizing HIV Care for People Aging with HIV: Incorporating New Elements of Care

- https://ryanwhite.hrsa.gov/sites/default/files/ryanwhite/grants/aging-guide-new-elements.pdf

Meeting the Needs of People Aging with HIV

- https://oneill.law.georgetown.edu/wp-content/uploads/2021/05/Meeting-the-Needs-of-People-Aging-with-HIV.pdf

Growing Older With HIV/AIDS: New Public Health Challenges

- https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3673522/

Cultural Competency, Discrimination, Health Care, HIV/AIDS, Legal & Financial, LGBTQ+ Aging, Social Isolation | What is Old & Bold: Services for All?

- https://www.sageusa.org/get-involved/take-action/old-and-bold/

Older Adults with HIV/AIDS: A Growing Population

- https://acl.gov/news-and-events/acl-blog/older-adults-hivaids-growing-population

Demanding Better: An HIV Federal Policy Agenda by People Living with HIV

- https://www.pwn-usa.org/wp-content/uploads/2021/07/Networks-Policy-Agenda-FINAL.pdf

Creating a Framework for HIV Survival

- https://www.tpan.com/sites/default/files/TRP%20Roundtable%20Report%20-%20Creating%20a%20Framework%20for%20HIV%20Survival%20FINAL.pdf

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HIV + Hepatitis Policy Institute
JSI
National Working Positive Coalition
Positive Women's Network - USA
The Reunion Project
The Well Project
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