

40 ANNIVERSARY
OF THE DENVER PRINCIPLES
FROM PATIENT RIGHTS TO HUMAN RIGHTS



CONGRESSIONAL POLICY BRIEF ON **HIV AND AGING**

RAYBURN HOUSE BUILDING
WASHINGTON, DC
JUNE 14, 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 HEALTH CARE 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 brief 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 brief also honors the history and future of people over 50 aging with HIV.

About this Policy Brief

This policy brief 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 brief 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 Brief 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.

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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.





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>



ACKNOWLEDGEMENTS

This commemoration of the 40th Anniversary of The Denver Principles would not have been possible without the generosity and support of our two event sponsors, Gilead Sciences, Inc., and ViiV Healthcare. A special thank you to Darwin V. Thompson, Director, Corporate Giving Public Affairs, Gilead Sciences, Inc., for his commitment and support of the 40th Anniversary of the Denver Principles would not be possible.

Thank you to Vanessa Johnson and Linda H. Scruggs, Ribbon's Co-Executive Directors of Ribbon, and Shauna Cooper, Director of Programs, for their leadership of the ROC4Aging+ HIV Age Positively Initiative. We also thank our co-sponsor, the U.S. People Living with HIV Caucus led by Ronald Johnson.

We appreciate the following organizations' and individuals' investment and response to the critical issues that people aging with HIV are facing domestically:

Members of the ROC4Aging+ Policy Action Group

- William McColl, Lead Co-Chair; Vanessa Johnson, Staff Support Co-Chair
- Members (in alphabetical order) Ed Barron, Olga Irwin, Ronald Johnson, Matthew Lesieur, Jules Levin, Murray Penner, and Terri Wilder

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Moises Agosto (NMAC), Scott Bertani (HealthHIV), Jeff Berry (The Reunion Project), Waheedah El-Shabazz (The Reunion Project), Kelly Flannery (PWN-USA), Joe Huang-Racalto (NMAC), Ronald Johnson (US. People Living with HIV Caucus), Naina Khanna (PWN-USA), Mark Misrok (National Working Positive Coalition), Murray Penner (U=U), Venita Ray (Consultant), Malcolm Read (THRIVESS), and Sean Strub (Sero Project), Carole Treston (Alliance of Nurses in AIDS Care), and Terri Wilder (SAGE)

Thank you to the DP40 Auxiliary and Supporting partners (listed in alphabetical order):

AIDS Foundation of Chicago (AFC), AIDS United, amfAR, HealthHIV, Lancet, Latino Commission on AIDS (LCOA), National Association of State and Territorial AIDS Directors (NASTAD), NMAC, and POZ Magazine

Thank you to the DP40 Supporting partners (listed in alphabetical order):

Association of Nurses in AIDS Care (ANAC), HIV+HEP Policy Institute, JSI, National Working Positive Coalition (NWPC), Positive Women's Network-USA, SAGE, SERO Project, SisterLove, The Elizabeth Glaser Pediatric AIDS Foundation, The Reunion Project, and The Well Project

Thank you to the DP40 Collaborators (listed in alphabetical order):

FAPP Aging Working Group, Five Horizons Health Services, HANC's Legacy Project, HIV and Aging Research Project, National HIV Aging and Advocacy Network (NHAAN), San Francisco AIDS Foundation, The Elizabeth Taylor 50-Plus Network, THRIVESS's Silver Lining Project and Whitman-Walker

Finally, we acknowledge and thank the following for their guidance and support:

- Harold Phillips, Director, White House Office on National AIDS Policy, for his leadership.
- The staff of Representative Barbra Lee's Congressional Office for their encouragement.
- Meeting Masters, Inc., for helping the event organizers create a memorable experience.

Sponsors

Gilead Sciences, Inc.
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Five Horizons Health Services
HIV + Hepatitis Policy Institute
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National Working Positive Coalition
Positive Women's Network - USA
The Reunion Project
The Well Project
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SERO Project
SisterLove
Whitman-Walker Institute

Media

The Lancet
POZ

