HIV & AGING

Older Adults Living and Thriving with HIV

INTRODUCTION

June 5, 2021, will be the 40th anniversary of the Centers for Disease Control and Prevention's *Morbidity and Mortality Report* issue that announced the first reported cases of the disease that came to be known as AIDS. It is a huge understatement to say much has changed over four decades. AIDS cases grew to be a worldwide HIV epidemic. We have moved from the early hopes of a vaccine, to the despair of an AIDS diagnosis being a near certain death threat and hundreds of thousands lives lost, to the seeming "miracles" of antiretroviral therapy, to local, state, and national planning to end the HIV epidemic. One of the remarkable results of this transition in the HIV epidemic is the growing number of persons living with HIV who are 50 years and older, many of whom have been living with HIV for 25 or more years. The U.S.[1] and the rest of the world are seeing the first generation of people 50 years and older who are aging with HIV. Indeed, we are now seeing people living with HIV who are 65 years and older, many of whom may live into their late 70s and 80s.

The large and growing number of older adults living with HIV, and older adults' increasing percentage of the total number of people living with HIV, is certainly a benefit. The increasing number and percentage have also revealed challenges and barriers for older adults living with HIV and challenges for service providers, researchers, government agencies and public policymakers. The challenges and barriers that have surfaced over the years center on the interrelationship between the impact of the aging process on HIV infection, the impact of HIV on the aging process, and the physical and mental health conditions that are associated with aging. Additional challenges arise from the various ways social determinants of health, including stigma and discrimination, impact older adults living with HIV.

As early as the mid-1990s, there were voices alerting the HIV/AIDS community and public policymakers to the emerging challenges of HIV and aging. Many of those early alerts were coming from people living with HIV. Advocacy for greater recognition of the issues surrounding HIV and aging, and increased responses to the needs and concerns of people aging with HIV, were steady, although often overlooked, throughout the 2000s. Within the past five years, however, the awareness of and sense of urgency about HIV and aging have increased notably. Older adults living with HIV telling their stories and being joined by advocates and researchers have made the challenges of HIV and aging more notable. The challenges and barriers related to HIV and aging remain but the heightened awareness and sense of urgency have increased the hope for real changes.

An example of the type of barriers that confront older adults living with HIV, and the importance of advocacy, is the recent attempt by the U.S. Department of Health and Human Services to make a critical change to prescription drug coverage under Medicare Part D. Part D is an optional benefit within Medicare that provides beneficiaries access to affordable prescription drugs. The legislation that created Part D established six "protected classes" of drugs to safeguard access to lifesaving medications. The law also requires Part D prescription drug coverage plans to cover "all or substantially all" within the six protected classes. One of the drug classes is antiretrovirals. The six protected classes policy means that Medicare beneficiaries living with HIV have access to the full range of antiretroviral medications.

In November 2018, HHS proposed a rule that would have allowed Part D prescription drug plans under certain conditions to exclude drugs within a protected class. The proposed rule would have also allowed plans to require prior authorization for some prescribed drugs and would have removed restrictions against "step therapy."

The proposed rule was seen by many people in the HIV community and in other chronic health care groups as a serious threat to Medicare beneficiaries' health, well-being and life. Following strong opposition to the proposed changes, HHS issued a final rule that left the policy on protected drug classes largely intact and limited the allowances for prior authorization and step therapy.

AIDS United recognized the threat that the proposed rule posed for older adults living with HIV who had Part D drug coverage and was very active in opposing the proposed rule. AIDS United, and the partner organizations that make up its Public Policy Council, also saw opposition to the proposed rule as recognition of the need for more focused policy and advocacy on HIV and aging and on the urgent needs and concerns of older adults living with HIV. Acting on these recognitions, AIDS United initiated its HIV & Aging project, with support from Gilead Sciences.

An important component of the project was HIV and aging listening sessions conducted in summer 2019. The sessions were conducted in partnership with Public Policy Council member organizations and held in 12 cities across the country, including in Puerto Rico.* Listening sessions were also held at AIDSWatch 2019 and the 2019 U.S. Conference on AIDS. The purpose of the sessions was to hear directly from older adults living with HIV about their experiences and their observations of and comments about services and service delivery to inform AIDS United's policy and advocacy on HIV and aging issues. The participants reflected the diversity of people living with HIV in terms of race and ethnicity, sexual orientation, gender identity, lived experiences, and the various years of 50+. In the sessions, the facilitators heard directly the challenges and barriers that older adults living with HIV face and the gaps in services they experience.

Medical Health Care

- Difficulties in accessing health coverage and care, including being denied private health insurance.
- Difficulties in maintaining continuity of care when shifting from one health insurance plan to another or shifting from private insurance to Medicaid or Medicare.
- Difficulty managing health care, especially HIV care and care for numerous comorbidities and age-related chronic health conditions.
- Dealing with polypharmacy issues, including the interaction between HIV medications and medications for non-HIV related conditions.

"I don't want to see 10 different providers in one visit; I'd prefer to see one or two maximum who can take care of all my needs."

* Birmingham, Alabama; Chicago, Illinois; Columbus, Ohio; Fort Lauderdale, Florida; Houston, Texas; Miami, Florida; Milwaukee, Wisconsin; New Orleans, Louisiana; New York, New York; Portland, Oregon; San Francisco, California; and San Juan, Puerto Roco.

- Gaps in the knowledge and experience of health care providers.
  - Knowledge of and experience with aging's impact on HIV.
  - Knowledge of and experience with the impact of HIV on aging and on non-HIV conditions (e.g., cardiovascular disease and diabetes).
- Concerns about long-term and nursing care.

Mental Health Care and Alcohol and substance use

- Lack of mental health and alcohol and substance use treatment programs for older adults. Much concern expressed about:
  - Depression and anxiety.
  - Trauma and its effects.
  - Alcohol and substance use.
  - Availability of syringe services programs.

> "I know more dead people than living people."

Loneliness and Social Isolation

- Experiences of loneliness and social isolation is a major, pervasive issue.
  - Lack of programs that deal with loneliness and social isolation.

> "Will I ever find love, or will I be lonely forever?"

Stigma and Discrimination

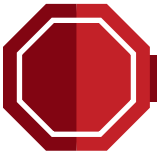
- Stigma and discrimination are still real for all people living with HIV, including older adults.
- Stigma and discrimination that are heightened by ageism, and intersectional issues of racism, sexism, gender identity discrimination, homophobia and transphobia.

> "And we, even right here in this city, I was working with [deleted]. My manager came to me, said, 'You can't join the group because they said if you bring any food to Christmas or stuff like that, that we're not going to eat it. That if you touch anything, we're not going to eat it."

Housing, Transportation, and Other Support Services

- Inadequate social and support services, most notably lack of adequate, safe, and affordable housing and inadequate access to transportation.
- Concern for decreased funding for support services under the Ryan White HIV/AIDS Program; loss of buddy programs cited as an example.

> "Support services are dissolving."



Ending the HIV Epidemic

- Concerns with what the emphasis on ending the HIV epidemic means for older adults living with HIV.

> "...if we're going to end this epidemic, there has to be a plan for the aging community."

The facilitators also heard about programs that are working well in meeting the needs of older adults who are living with HIV and heard of staff who were sensitive to the needs of older adults living with HIV. There were also many comments from participants noting the importance of and benefits from the Ryan White HIV/AIDS Program, including the AIDS Drug Assistance Program.

DISCUSSION

At the end of 2017, the CDC reported nearly a half-million adults living with HIV were 50 years or older.[2] People 50 years and older made up nearly 50% of all adolescents and adults living with HIV in the 50 states, Washington, D.C., and dependent areas. Both the number of older adults living with HIV and their percentage of all people living with HIV in the U.S. are increasing. The increases are largely due to the success of antiretroviral treatment, implementation of a comprehensive array of evidence-based HIV prevention programs, and the conclusive evidence of treatment as prevention. Based on the 2017 numbers, it is likely that older adults living with HIV will constitute over 50% of all people living with HIV in 2020 and subsequent years. **Following a study, the Health Resources and Services Administration projects that by 2030 64% of people served under the Ryan White HIV/AIDS Program will be 50 years or older.[3]**

Older adults living with HIV are the majority of people living with HIV and will likely be the overwhelming majority over the next few decades in the absence of a complete cure for HIV infection. People living with HIV who were 20-29 years of age at the end of 2019 and have achieved and maintained viral suppression, remained in care, and are otherwise in good health will turn 50 starting in 2040. If they maintain viral suppression and good health, they will turn 70 starting in 2060.[4] Older adults living with HIV will be the prevailing face of HIV well into the last half of the 21st century. All people living with HIV are aging.

Despite the current and projected reality of the number of older adults living with HIV, the issue of HIV and aging is too often not seen as a high priority. Far too many older adults living with HIV feel that their needs and concerns are forgotten, given less attention, or ignored. Older adults living with HIV are a "forgotten majority."[5]

The challenges that were heard from the participants in the listening sessions were very real and unique to the individuals, but they were not unexpected. There have been numerous reports, articles and studies that have brought attention to HIV and aging and have described or forecast the challenges that older adults living with HIV face, and the inadequate level of programs and services and the gaps in services. Many of the reports, articles and studies have made numerous recommendations on what needs to be done to serve people living with HIV and to address the issue of HIV and aging.

There is also an extensive body of research on HIV and aging and on the needs and concerns of older adults living with HIV. Much more research is needed on the many questions that are not answered and for which there is not enough data or information, but there already is a growing knowledge base about HIV and aging and about older adults living with HIV.[6]

In addition to praiseworthy reports and articles and a growing body of knowledge, there are local programs operated by community-based organizations that are providing needed services to older adults living with HIV. As noted above, several participants in the listening sessions cited these programs. There are also local, state, and federal governmental programs and efforts that focus on HIV and aging and on providing services to older adults living with HIV.

Despite the knowledge that we have, the recommendations that have been made, and programs that are operating, there is the reality that not enough is being done; the reality that many older adults living with HIV experience being "forgotten." Older adults living with HIV are experiencing a real disconnect. On one side there is the current profile of the HIV epidemic as being made up largely of older adults, there is already a body of knowledge about HIV & aging and the needs of older adults living with HIV, and there are numerous recommendations that have been made on what needs to be done in response to HIV and aging. On the other side there is a health care system and current service delivery models that are not providing optimal care, treatment and supportive services to older adults living with HIV.[7] To summarize what was said in several of the listening sessions, there needs to be new approaches and new models of for providing treatment, care, and support for older adults living with HIV. There is a need for public policies and programs that end the disconnect and drive a comprehensive response to HIV and aging to achieve optimal outcomes for older adults living with HIV.

The listening sessions also made clear that new approaches to HIV and aging and new models of service delivery for older adults living with HIV should include a wider focus than achieving and maintaining viral suppression. In common with all older adults, people living with HIV who are 50 years and older want to thrive and to age successfully.[8] The well-being of the whole person should be the focus.[9]

There is an urgent need for **sustained, focused, and collaborative advocacy** to eliminate the disconnect that weakens the response to HIV and aging and leaves the needs and concerns of older adults living with HIV largely unmet. What follows are recommended priorities for a policy and advocacy agenda on HIV and aging. They are put forth as a suggested starting point for **sustained, ongoing policy and advocacy** on HIV and aging. The recommendations reflect what was heard by older adults living with HIV in the listening sessions. They also reflect the body of literature on HIV and aging and the literature on the needs of older adults living with HIV and the myriad challenges to meeting the needs.

POLICY AND ADVOCACY PRIORITIES

The recommended priorities are aimed at the federal government. The recommendations can be adapted to state and local governments.

Overall Principles

- Proposed public polices, and advocacy to achieve them, must be grounded in racial and ethnic justice and social and economic justice. Policies and advocacy must address the various inequities and disparities affecting older adults living with HIV. Particular attention must be given to addressing disparities and inequities affecting transgender older adults, older women, and older adults in Puerto Rico, the U.S. Virgen Islands, and the other U.S. dependent areas.

- Proposed public policies must address the various social determinants that affect the health and well-being of older adults living with HIV.

» Beyond policy and advocacy specific to HIV and aging and the needs and concerns of older adults living with HIV, HIV-related policy and advocacy and policy and advocacy related to older adults should address how these policies impact older adults living with HIV.

Vision

All people living with HIV in the United States will receive the care and support needed to age successfully, having achieved and maintained good physical, mental, and sexual health and overall well-being.

Goals

1. Inclusion of policies, programs and research that address HIV and aging and the needs and concerns of older adults living with HIV in the broader response to HIV and efforts to end the HIV epidemic.

2. Recognition of HIV prevention, care and treatment, and research as a routine component of physical and mental health care for older adults and a routine component of social support services for older adults.

Priorities: Medical Care

- Advocate the development of funding opportunities under the Ryan White HIV/AIDS Program for programs or program components that are designed specifically to demonstrate and replicate innovative models of comprehensive care and treatment to improve the health outcomes of older adults living with HIV. Models of care shoud demonstrate:
    - Patient-centered care.
    - Inclusion of care and treatment of age-related chronic conditions and non-HIV related comorbidities in HIV care and treatment or coordination between HIV care and care and treatment of age-related chronic conditions and comorbidities.
    - Management of polypharmacy and educating clients about polypharmacy.
    - Adherence to HIV treatment guidelines for older adults that are included in Guidelines for the Use of Antiretroviral Agents and HIV-1 Infected Adults and Adolescents.
    - Assistance and support for older adults whose health coverage shifts to Medicaid or Medicare.
    - Inclusion of geriatric assessment and care into HIV clinics.

- Advocate support for increased medical case management services under the Ryan White HIV/AIDS Program for older adults living with HIV.

- Advocate the development by the Health Resources and Services Administration of policies and funding that promote the inclusion of health care for older adults living with HIV in non-HIV related programs it administers.

- Oppose legislation and administration policies that would result in drastic changes to Medicare or result in substantial reduction in benefits and coverage, including prescription drug coverage under Medicare Part D.

- Oppose legislation and administration policies that would result in drastic changes to Medicaid, including efforts to convert Medicaid into a block grant that caps federal funding, or result in substantial reduction of benefits, coverage and eligibility.

- Oppose legislation and administration policies that would repeal or undermine the Affordable Care Act.
- Advocate legislation that would:
  - Prohibit prior authorization and other barriers to accessing prescription drugs for older adults living with HIV.
  - Increase health coverage and access to care for non-HIV related comorbidities for older adults living with HIV.
  - Increase health coverage and access to care for people living with HIV who are 50-64 years of age.
- Support legislation and federal policies that would eliminate gap in health coverage and access to care and medications in Puerto Rico and the other U.S. dependent areas.
- Advocate increased support for training and education programs under the Ryan White HIV/AIDS Program and other Health Resources and Services Administration bureaus that would:
  - Increase knowledge of health care professionals of the impact of aging on HIV and knowledge of non-HIV related comorbidities of older adults living with HIV.
  - Increase the cultural competency and sensitivity of health care professionals who provide care and treatment to older adults living with HIV.
  - Increase the knowledge of health care professionals on the impact of HIV on non-HIV related comorbidities.
- Advocate legislation and federal policies to increase access to affordable long-term care for older adults living with HIV.

Priorities: Mental Health and Substance and Alcohol Use Disorders

- Advocate increased support and funding under the Ryan White HIV/AIDS Program for programs or program components that are designed to provide mental health screening and care for older adults living with HIV.
- Advocate legislation to provide increased support and funding for programs that are designed to:
  - Meet the mental health needs of older adults living with HIV.
  - Provide prevention of and treatment for substance and alcohol use disorders for older adults living with HIV.
  - Address high prevalence of loneliness and social isolation among older adults living with HIV.

Priorities: Housing, Transportation, and Other Support Services

- Advocate expansion of support services provided under the Ryan White HIV/AIDS Program, with an emphasis on case management services, food and nutrition programs, transportation, and programs that address loneliness and social isolation among older adults living with HIV.
- Advocate legislation and administration action that ensures inclusion of older adults living with HIV in federal programs that provide supportive services to older adults, including programs under the Older Americans Act.

- Advocate expansion of housing and housing assistance provided under the Housing Opportunities for Persons with AIDS Program for older adults living with HIV.
- Advocate an assessment of eligibility of older adults living with HIV for federal programs that provide housing and housing assistance for low-income people and advocate elimination of barriers to accessing housing and housing assistance by older adults living with HIV.

Priorities: Stigma and Discrimination

- Advocate Congress, the administration and federal agencies to recognize and take concerted action to reduce persistent levels of stigma and discrimination experienced by older adults living with HIV.
    - Recognition of the intersectional impact on older adults living with HIV of ageism, racism and ethnic discrimination, homophobia, transphobia, ableism, gender discrimination, and discrimination against people with histories of substance use disorders and people with histories of incarceration.

Priorities: Ending the HIV Epidemic

- Advocate the inclusion of the needs and concerns of older adults living with HIV in all federal, state, and local plans or initiatives to end the HIV epidemic.
- Monitor federal, state, and local plans or initiatives to end the HIV epidemic to insure inclusion of strategies to maintain and grow as needed HIV prevention programs and HIV care and treatment.

Priorities: HIV Policy and Advocacy and Older Adult Policy and Advocacy

- HIV policy and advocacy and older adult policy and advocacy must include HIV and aging and the needs and concerns of older adults living with HIV as **ongoing and integral components of the work**. Particular attention should be given to how proposals to reform health care systems, and proposals to change or transform Medicaid and Medicare will impact older adults living with HIV.
- Both areas of policy and advocacy must work to increase government, media, and the public's awareness of the rising number of older adults living with HIV.

CONCLUSION

There is much that is known about HIV and aging and much that still needs to be known. There is much that is known about the needs and concerns of older adults living with HIV and the challenges that older adults living with HIV face in their daily living and managing their health and well-being. The needs, concerns and challenges are still evolving and emerging. But there is still not enough recognition of HIV and aging and not enough collaboration between the field of HIV prevention, care and treatment, research, and advocacy and the field of geriatrics and services and advocacy for older adults. And too many older adults living with HIV feel that they are "forgotten." Too often, that feeling reflects reality.

This situation does not need to be accepted and should not be accepted. There should be movement to achieve the vision of all older adults living with HIV aging successfully with good health and well-being. Older adults living with HIV deserve sustained advocacy to address HIV and aging and to address their needs and concerns. It must be remembered that **all people** living with HIV are aging.

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Thanks to and gratitude for the older adult men and women living with HIV, long-term survivors of

END NOTES

[1] Throughout this paper, U.S. refers to the 50 states, the District of Columbia, and the six dependent areas.

[2] CDC. HIV Surveillance Report, Diagnoses of HIV Infection in the United States and Dependent Areas, 2018 (Preliminary), vol. 30. **https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-report-2018-vol-30.pdf**. Published Nov. 2019

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[9] Healthy and successful aging has been called "the fourth 90," referring to the 90-90-90 targets for the response to HIV. See: Harris, T.G. et. al. "Achieving the Fourth 90: Healthy Aging for People Living with HIV." *AIDS*, 32(12), 1563-1569. 2018. doi: **10.1097/QAD.0000000000001870**.