Navigating Aging and HIV: Insights and Recommendations from Consumers and Providers

May 2025

Executive Summary

Older adults living with HIV are an underserved and often overlooked population facing intersecting challenges that threaten their health, dignity, and quality of life. Drawing on focus groups conducted in New York City and survey data from the ACRIA Center at GMHC, this paper outlines four major areas of concern: (1) Isolation, Mental Health, and Belonging; (2) Stigma, Ageism, and Sexual Wellness in Older Adulthood; (3) Housing, Financial Instability, and Gaps in Healthcare Access; and (4) Building Provider Capacity to Serve Older Adults Living with HIV. This brief report amplifies the voices of older people living with HIV, many of whom feel invisible in healthcare and social service systems, and offers actionable recommendations for healthcare providers, service providers, and community-based organizations. Findings suggest that coordinated, culturally responsive, and age-inclusive services are urgently needed to support wellness across the lifespan for people aging with HIV.

INTRODUCTION

As the number of older adults living with HIV continues to grow, there is an urgent need for programs and providers to respond to their lived realities and support their sexual wellness, holistic health, and overall quality of life. Currently, more than 50% of people in the United States living with HIV are over 50[1]. By 2030, nearly 70% of people living with HIV in the United States will be aged 50 or older[2]. Yet, the experiences of aging adults with HIV remain underrepresented in public health messaging, program design, and provider training. This white paper reflects an effort to better understand the evolving needs of older adults living with HIV in New York City.

METHODS

This paper draws from two sources. First, three focus groups were conducted with older adults living with HIV in New York City between January and May 2025 by the ACRIA Center. Focus group participants (N < 30; ages 50–81) represented a wide range of racial, gender, and sexual identities, including Black, Latine, White, and multiracial participants, as well as gay, bisexual, heterosexual, and transgender individuals. Discussions were designed to be affirming and conversational, with guiding questions focused on sexual health and wellness, general healthcare concerns, social connection, and reactions to sample media campaign materials. Sessions were conducted both in person and virtually, with a facilitation style grounded in accessibility, community care, and mutual learning. Analysis was drawn from audio recordings, facilitator notes, and direct observation. Participants gave informed verbal and written consent and received modest compensation for their time. In parallel, a survey of over 35 healthcare and service providers, including clinicians, case managers, peer workers, and outreach staff, collected insight on organizational capacity, perceived client needs, and gaps in existing services.

Together, the perspectives of participants and providers form the basis of the four core themes that emerged across focus group discussions and survey responses. These themes reflect interconnected dimensions of older adults' experiences and point to persistent gaps in care and connection. Each theme is presented with a summary of what providers reported as well as what participants

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[1] Namkung, A. (2024, May 23). Supporting research for older adults living with HIV. National Institute on Aging. https://www.nia.nih.gov/research/blog/2024/05/supporting-research-older-adults-living-hiv

[2] WING E. J. (2017). The Aging Population with HIV Infection. Transactions of the American Clinical and Climatological Association, 128, 131–144.

said, followed and targeted recommendations to strengthen service delivery, improve health equity, and advance dignity and wellness for older adults living with HIV:

- 1: Isolation, Mental Health, and Belonging
- 2: Stigma, Ageism, and Sexual Wellness in Older Adulthood
- 3: Housing, Financial Instability, and Gaps in Healthcare Access
- 4: Building Provider Capacity to Serve Older Adults Living with HIV

DISCUSSION

THEME 1: Isolation, Mental Health, and Belonging

Provider experiences:

Providers consistently identify social isolation and mental health as major unmet needs for older adults living with HIV. Some respondents note existing services such as supportive counseling groups or co-located health and senior center programming, but many emphasize that these remain inaccessible or insufficient. There is a notable lack of in-person support groups tailored specifically to older adults, with Providers note that many programs are targeting gay men in promotion and recruitment. Several providers underscore the urgent need for more culturally competent mental health services, especially for those facing compounded stigma due to age, race, gender, or sexual orientation, and parenting status. Emphasis was put on resources needed for people of color, and transgender individuals.

Staffing shortages and communication barriers emerged as critical gaps. Providers expressed concern that older adults often leave healthcare encounters feeling confused or unsupported, lacking clear understanding of their care plans. There is a strong call for more hands-on care coordination, particularly for low-income and technologically limited older adults who struggle to navigate complex systems independently in an increasingly web-based service provision system.

Community experiences:

Participants emphasized that social isolation shows up in their lives as a deep absence of regular connection to others, lack of opportunities to express their hobbies and interests, and exposure to new experiences. Many shared that, following the COVID-19 lockdown, the community spaces and support systems they once relied on have either disappeared or changed dramatically. Although public life has resumed, their sense of belonging has not. Some described distancing themselves by choice from spaces that felt emotionally unsafe, chaotic, or exploitative. Others cited transportation difficulties, fatigue with virtual programming, and a lack of awareness of culturally relevant offerings as significant barriers to engagement.

Mental health was central to overall well-being but often remains inadequately supported. Participants described navigating grief, loss, aging, and living with HIV with limited access to consistent, formal resources. Those with access to affirming therapists or peer support groups highlighted their vital role in fostering resilience and hope. Across all groups, there was a clear longing for integrated mental health approaches that include storytelling, creativity, humor, and joy as forms of healing and community-building. Participants expressed a strong desire for in-person opportunities to gather, express themselves, date, attend events, and explore their identities as older adults living with HIV.

Key barriers to reconnection included:

- Limited or unclear information about available in-person programming
- Physical and financial challenges related to transportation and limited service availability outside Manhattan and Brooklyn
- Fatigue with virtual programs and web-based assistance
- Deliberate avoidance of previous social hubs associated with gossip, drug use, or financial abuse
- Lack of safe spaces to gather with other long-term survivors (LTS) and HIV-positive individuals

Despite these challenges, participants expressed a deep desire for safe, consistent, and low-barrier spaces to connect with peers, express themselves, and participate in joyful, meaningful experiences. Desired activities included but were not limited to:

- Broadway shows and movies
- Boat rides, walks, and outdoor events
- Brunches and picnics
- Dances, parties, and social gatherings
- Creative writing groups and discussion circles
- Opportunities for young children of parents with HIV to engage in social activities

Participants also expressed interest in and tools for:

- Conversation starters to educate family members about HIV
- Language classes to bond with younger grandchildren, nieces, and nephews
- Continued in-person support groups, especially for long-term survivors, women, individuals in addiction recovery, and others whose experiences fall outside the predominant gay male demographic

Participant quotes:

- On pre-pandemic gathering:
  - “I think of pre-pandemic. I think of how active I was and how easy it was to do...And after the pandemic, people, they actually want to touch. But they can't because of this big thing that we have, that we went through a few years ago. [Now] it's four years later and it's really difficult. And people are still kind of like learning that, you know, oh, ‘can I touch you?’ And we're human. We need to be held, we need to be touched, we need to be kissed. We want to, you know. And that's kind of been a struggle. It's like, uh, move your left arm, move your right arm, move your left arm, you know. So it's been a challenge”
- On support groups:
  - Women’s group: “It was great. I had somebody to talk to, share my problems. We might have the same problems, we might not have the same problems, this and that. It was fantastic. It was the unity we had, the identification with certain issues. And when it was in person, that's where we became close. When the Zoom came in [I decided] ‘I'm not attending the Zoom, I can't stand the Zoom’”
  - Creative writing: “Every Tuesday, we have creative writing. I write poems on feelings. Or what a difference a day makes. Or whatever you feel. Or see your eyes. My eyes tell a story. Cause they open. I can see the beauty of the trees, the flowers, the ocean...”
- On enjoying their own company
  - “The most important thing I've learned in my life is that I like my own company. I love being alone... the older I get the less I wanna settle because I value myself and I value my, I value how I use my time and I'm not gonna settle for less. Because I did the work to become the person that I am and I don't feel like going backwards”

THEME 2: Stigma, Ageism, and Sexual Wellness in Older Adulthood

Older adults living with HIV continue to confront layered stigma related to both their HIV status and age. Sexual wellness is frequently overlooked in clinical and community-based settings due to provider discomfort, structural ageism, and persistent societal taboos. Participants described a wide spectrum of sexual and romantic needs: from the desire for intimacy, companionship, and flirtation to the need for safety and autonomy in navigating new relationships. Yet these needs often go unmet in service environments that are either silent on or judgmental about older adults' sexual lives.

Provider experiences:

Stigma and ageism remain pervasive in how sexual wellness services are designed and delivered to older adults. Although organizations such as SAGE, GMHC, Callen-Lorde, and ACRIA offer education, counseling, and referrals related to sexual health, providers widely report that many services fail to address the specific needs of aging populations. Several noted that HIV-related services are often tailored to younger people, leaving out older adults.

Providers called for an end to assumptions that older adults are no longer sexually active. They emphasized that sexual health education should be universally provided, without age-based exclusion, and should reflect a diversity of experiences and identities. Respondents also recommended more public campaigns to normalize and destigmatize aging sexuality, and suggested blending sexual health education with content on empowerment, intimacy, and personal development to build trust and engagement.

Community experiences:

Participants shared that while their desire for sexual activity fluctuates in different directions - some seek to maintain or increase sexual activity, while others notice shifts in libido or interest. Across all activity levels, a consistent longing emerged for connection, intimacy, and affirmation. Some described enjoying their own company and exercising discernment in relationships, particularly avoiding past environments that felt unsafe or exploitative. Others shared feelings of frustration and vulnerability in dating - especially with younger partners who sometimes assumed financial gain or held unclear intentions.

They also highlighted that navigating sexuality in later life requires addressing intersecting concerns such as grief from partner loss, evolving dating norms, bodily changes, safety considerations, and technology use. Many longed for more nuanced conversations and resources that respect their lived experiences, relationship preferences, and emotional needs. Concerns about contracting additional sexually transmitted infections (the recent monkeypox outbreak[3] was named) were noted to occasionally deter participants from seeking new connections.

Overall, the desire for supportive spaces and ongoing need for public skill-building and personal empowerment workshops was clear.

Participant quotes:

- On joy in flirtation, courtship, and connection outside of physical sex:
    - “To me, sex isn't always the actual act. I have a lot of fun in the kitchen. I have a lot of fun going into the farmer's market and the flirting and being courted...”
- On the fear of additional STDs
    - “There's too many STDs out there. My doctor even said ‘oh, you should have sex again’ I disagree. Last year was the monkeypox thing! I have a fear of getting another STD, so I don't really look for sex anymore. I's nice to find love in your life, but I really don't need it with another person”
- Fear of aging out of their homes
    - “I'm at that age now where people are getting sick, they're in their seventies, and I'm really overwhelmed by people I know who have to go into an old age home and they have to leave their home. And it's like, you, you don't know what to say...”
- Fear of financial exploitation in dating:
    - “The people that I attract always...have a hidden agenda. It's always like ‘oh, so you wanna see me? Can I get an Uber? Can a friend come? I know you're paid at your age. You should have a ton of money’. So am I dating people who are looking for a pillow for finances? So upon bringing anyone to my house, I feel I need to be safe. I don't invite just anyone. So the apps are absolutely not working for me. If I meet somebody outside and they're quick to [be] like ‘let’s go back to your place’”
    - “I'm a man of a certain age. I remember back in the day when we could walk down the street and somebody catch your eye and that

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[3] New York City Department of Health (2023, February 1). *New York City declares end to Mpox outbreak after nation-leading response. New York City Declares End to Mpox Outbreak After Nation-Leading Response - NYC Health.* https://www.nyc.gov/site/doh/about/press/pr2023/nyc-declares-end-to-mpox-outbreak.page

> was it. No questions asked. This is not happening anymore. And then you find out when you become a man of a certain age. People aren't as attracted to you as when you were younger, and the ones who are attracted to you are the young ones, youngins, who figure they can get something from you because you're older. I met this guy, and I brought him home and everything...We had a little entanglement. And because of my apartment and my building, before he left, he was going to charge me! I thought 'Oh, no. Oh, no!"...I'm thinking he's cute and he flirted [with me] but then I had to realize... 'This MF is young and a hustler and he figures I live in this building. I got all this money!...'"

Theme 3: Housing, Financial Instability, and Gaps in Healthcare Access

Provider experiences:

Providers emphasize that the intersection of financial instability, housing insecurity, and systemic healthcare barriers poses a compounding threat to older adults living with HIV. Many note that these adults often face:

- Persistent financial stress, including difficulty affording medication, premiums, and basic living costs, despite long-term adherence to care.
- Lack of access to affordable, stable, and accessible housing, particularly for those not actively using substances, with many supportive housing programs are designed around substance use recovery, excluding those with other needs
- Healthcare navigation challenges, including difficulty advocating for themselves, trouble accessing tech-based systems, and limited provider capacity to explain processes step-by-step
- Structural barriers, such as restrictive insurance policies that deny age-appropriate preventative care to people aging with HIV who may face earlier onset of health complications.
- Cognitive impairments affecting medication adherence and care coordination
- Insufficient provider education around aging with HIV, sexual wellness, and comorbidities for all doctors
- Stigma and ageism in healthcare settings, which contribute to older adults feeling invisible, ashamed, or reluctant to seek care and support.

Several providers also noted the long-term psychosocial toll of surviving the AIDS crisis, compounded by governmental inattention to this population’s evolving needs. There is a call for increased staffing, more tailored programming, and stronger inter-agency collaboration to bridge service gaps for this aging demographic.

Community experiences:

Participants across focus groups consistently emphasized the urgent need for stable housing and assistance navigating complex systems often described as “impossible to figure out” alone. Many shared experiences of eviction, homelessness, or living in shelters - conditions that exacerbate difficulties in managing HIV and other health needs. Concerns about rising rents, long waitlists for supportive housing, and fears of aging into nursing homes that lack HIV-competent care were voiced.

Financial stress emerged as a common theme, with many relying on fixed incomes, SNAP benefits, or part-time work insufficient to cover essential expenses. Participants also described difficulties accessing consistent healthcare due to provider retirements without replacements, clinics losing their welcoming atmosphere, and paperwork requirements that delay urgent care. Those fortunate to have affirming providers underscored the rarity and profound impact of clinicians who understand both HIV care and the realities of aging.

Several participants requested increased availability of services in Spanish and other languages, noting that many materials and programs remain oriented toward younger, tech-savvy audiences. Barriers such as Zoom fatigue, complex telehealth platforms, and online-only appointments further complicate access for some.

Recurring concerns included:

- Navigating SNAP benefits and addressing food insecurity
- Gaps in general, grief, and group counseling
- Lack of availability of case management
- Lack of a robust and up to date referral network
- Fatigue with telehealth referrals and web-conferencing
- Beyond HIV care, participants noted the need for age-related medical assistance and broader aging supports, including help with taxes and other non-medical issues.

Participant Quotes:

- Fear of aging out of their homes
    - “I'm at that age now where people are getting sick, they're in their seventies, and I'm really overwhelmed by people I know who have to go into an old age home and they have to leave their home. And it's like, you, you don't know what to say…”
- Lack of a robust referral network for needs related to aging
    - “I would love to have a [single] place to call for a resource and to get recommendations. I get the same recommendations all the time…. I don't like to do it over and over and over again…some service that would be very, very useful. Somebody that was dedicated to elder care, elder health, elder law…”
- Being their own case managers, personal research
    - “I did [receive] case management, but we have to be our own social worker and the best place to look is YouTube. so much information is [there]. I've got information on YouTube that no doctor would ever gave me. I got support from my mental diagnosis - my psychiatrist never told me! I didn't wanna be alone [so] going on YouTube, I found information I would never know”
    - “So when years ago we said, keep your eyes on a prize - that’s some of the prize there.The fact that we're learning about HIV aging and comorbidities, a lot of people don't know that outside of the, the HIV community. And, they don't go to their appointments and their lab work are not being checked three months. [But] you're checking your cholesterol triglyceride, you're checking your liver health, So we have to be thankful that… right now, we'll go on MyChart and I don't have to make a call my doctor and be worried like we did back in the day, [I don’t have to]I wonder what my labs are like.
- On needs outside of medicine
    - “I’m turning 65 and I want to know what's for me government wise, tax wise, and other kinds of stuff… and what resources are out there for me. Because for the longest time as a gay man, everything was there, I didn't have to go look for it.”

Theme 4: Building Provider Capacity to Serve Older Adults Living with HIV

Provider experiences:

Survey data indicate a wide spectrum of readiness among NYC-based providers to meet the sexual health and wellness needs of older adults living with HIV. While some report being leaders in this area, the majority identify as either “trying but could use help” or “developing their supports.” Very few described themselves as fully prepared.

When asked about training needs, providers expressed high interest in a broad range of topics, particularly:

- Updates on HIV and aging (72%)
- Communication skills for discussing sexuality (65%)
- Outreach practices to older adults (58%)
- Sex positivity with older adults (58%)
- HIV, Aging, and the Law (56%)
- Working with older LGBTQ+ adults (54%)
- Substance Use, Older Adults, and HIV (51%)
- HIV and Stigma with Older Adults (51%)
- Aging with HIV and Co-Morbidities(51%)

Additional areas of interest included addressing stigma, end-of-life care, and facilitating intergenerational learning, suggesting providers are seeking tools that are not only clinical but also relational and culturally attuned.

Community Experiences:

Participants expressed deep appreciation for longstanding relationships with doctors familiar with their histories and HIV management. However, many shared fears and anxiety about transitioning to newer providers who may lack understanding of their unique health profiles and comorbidities. Concerns were also raised about access to trusted referrals when relocating outside New York, accompanied by worries about support availability from friends and family in other areas of the country.

To assist with navigating healthcare successfully, participants requested:

- Case management support and advocacy services
- Computer literacy classes to enhance technology access and navigation
- Lifestyle medicine programs offering coordinated care, including nutritionists and cooking classes

- Resources addressing common comorbidities such as cancer, diabetes, hypertension, osteoporosis, and mental health
- Information on treatment alternatives to daily pills, including injectable HIV treatments and side effect management
- Better coordination between services at community health clinics
- Clarity on the differences between medications from the US and those in other countries

Participant Quotes:

- On good healthcare
    - “The best doctor is the doctor who’s ahead of your needs, who proposes some things. For example,I finally got a bone density test and it's something that I would recommend anybody to do, but it came from my doctor who thought it was a good idea. Same thing, I used to be a smoker. He got me to get a scan for my lungs, you know, because with age comes with comorbidities, and having a good doctor is that you can catch them at the very beginning. I fought and won over two different type of cancers that way and it's because I was regular with my doctor visits and the blood work and they could see the sign early on. So I have a great doctor, the best”
    - “I've been with my doctor 29 years. I’ve had two doctors. My first doctor, I was with her for the first year and then she moved on and I've been with my second doctor, um, for 29 years and it is worth it. I don't do anything. I trust him. He has never gave me wrong advice, and I'm just grateful he's still here with me.”
    - **Doctor building their resilience**
        - “My family accepted me for having HIV before I accepted it. And I think that their strength, or whatever it is that they have, gave me some, to go on because when I first heard it - that I was positive. I thought I was going to die and did everything to make it happen. And all the time that I was doing it, I didn't die. So one time I got really sick and went to my doctor. And I think because of her spirit - that she's here to help me. And since I've done that, I've been undetectable for like 15, 20 years now”
- On doctor’s retiring, needing age-related assistance
    - “I have a lot of medical help. I've got a general practitioner I've been with for many years. He's as old as I am, so someday he will retire. I have other doctors for other issues that I'm dealing with, but there's certain things that, are just age related that I cannot get good results

- like having to do with shoes and orthotics. When you go to a podiatrist these days, all they are are surgeons. I need to go someplace and I need to get different kinds of inserts - I'm missing a toe - different things in my shoes that are not necessarily a doctor related, but foot related that has to do with health. And there are many things like that. And there's a big gap in elder care.

- Experiences with clinics, doctors only concerned about HIV status or one ailment at a time
    - “Since I've been diagnosed, I've been to the doctor's office...and they just are treating me for my HIV status. They don't look at anything else, though. They treat also treat me for pain that I have in my feet, but they [are] just concerned really about HIV and that’s it. And it's different doctors. I don't see the same doctors. I see different doctors. It's confusing.”
    - “What used to aggravate me was being in a clinic, every time I had to go for another issue with a different part of my body, I had to go all around the world. So they send me to this hospital for ENT. They send me to this hospital for pulmonary, they send me to this hospital for a mammogram and it got to be too much...I'm more comfortable with my primary doctor than I am with my infectious disease doctor. 'cause the ID clinic is where everything changes. I have a whole bit, every time I go, I see somebody different. But my primary care, I always see the same doctor, always.

RECOMMENDATIONS

Drawing from the lived experiences of older adults living with HIV and insights from healthcare providers, these recommendations address key gaps in holistic care, sexual wellness, social connection, and resource navigation. They offer concrete, audience-specific strategies to improve culturally responsive, accessible, and comprehensive services. For healthcare providers, the focus is on enhancing clinical competence in aging-related HIV care and normalizing sexual health discussions. For community-based organizations, recommendations emphasize social engagement, integrated health programming, digital access, and psychosocial support. Together, these actions aim to reduce stigma, foster connection, and promote well-being across healthcare and community settings.

For Healthcare Providers

Holistic, Competent Care for Older Adults Living with HIV

- Prioritize training on HIV and aging, including comorbidities, drug interactions, and age-related concerns like cognitive decline, mobility issues, and chronic fatigue.
- Offer routine screenings and referrals for conditions frequently co-occurring with HIV, including diabetes, cancer, hypertension, osteoporosis, and kidney disease.
- Provide information on treatment alternatives such as long-acting injectables and support patients experiencing pill fatigue.
- Educate patients on U.S.-approved medications compared to global alternatives, emphasizing drug safety and regulatory context.
- Offer referrals and recommendations for pain management strategies beyond narcotics, especially for those with coexisting conditions.
- Integrate holistic and lifestyle medicine approaches into care settings—connecting patients with dietitians, weight management consultants, and mind-body wellness programs.

Sexual Wellness & Intimacy

- Normalize conversations about sexual activity and wellness in older adulthood.
- Screen for STIs regularly, regardless of age
- Support patients with low-pressure ways to initiate conversations with partners, especially around shifting intimacy or sexual interest.
- Affirm diverse relationship structures, including ethical non-monogamy and polyamory.

For Service Providers and Community-Based Organizations (CBOs)

Sexual Health and Social Connection

- Host in-person social outings and “mixers” to foster dating, friendship, and social engagement among older adults living with HIV.
- Develop workshops on non-traditional relationship models, such as polyamory and ethical non-monogamy.
- Create discussion-based resources that support older adults in navigating intimacy, changing libido, and evolving partner dynamics.

- Develop workshops to support older adults re-entering the dating landscape, covering topics such as digital dating norms, safety, intergenerational relationships, and building confidence in 2025's dating culture.

Integrated, Accessible Health Programming

- Develop or partner with lifestyle medicine clinics that offer bundled services: nutrition counseling, cooking classes, movement/exercise groups, and chronic condition management.
- Provide culturally and linguistically competent services, including Spanish-language programming and printed materials for clients with limited digital access.
- Incorporate spiritual wellness, trauma support, and mental health resources into broader HIV-related care.

Combat Isolation & Digital Barriers

- Offer tech literacy workshops and alternatives to Zoom-based programming for clients with digital fatigue or access issues.
- Provide ongoing, in-person support for navigating healthcare systems, housing waitlists, and SNAP or SSI enrollment processes.

Navigation, Advocacy, and Psychosocial Support

- Assist clients in identifying affirming primary care and HIV specialists (especially for those relocating or aging out of current services).
- Offer educational materials on the interplay between HIV and other chronic illnesses (e.g., inflammation, prostate issues, cognitive decline).
- Respond to requests in-person for resources on non-medical aging needs, such as retirement planning, tax assistance, and grief counseling.
- Increase referrals to programs focused on long-term survivors and those aging with HIV-related complications and regularly update network based on feedback and quality assurance.

CONCLUSION

Meeting the evolving needs of older adults living with HIV requires a sustained commitment to empathetic, knowledgeable, and integrated care. By centering their voices and the expertise of providers, these recommendations offer a roadmap to reduce isolation, stigma, and systemic barriers. Implementing these strategies will help build supportive environments where aging with HIV is met with dignity, respect, and comprehensive wellness. Continued collaboration across healthcare and community sectors is essential to advancing health equity and improving outcomes for this growing population.

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Contact Information:

For additional information/to learn more contact:

E-mail- ACRIA@gmhc.org

Tel: (212) -367-1000