

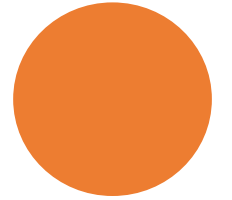
# Empowering Wellness: Strategies for Enhancing Home and Community- Based Services for Older Adults with HIV

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# Welcome and Introductions

***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.*


***SAGE** is the world's largest and oldest organization dedicated to improving the lives of LGBTQ+ elders. Founded in 1978 and headquartered in New York City, SAGE is a national organization that offers supportive services and consumer resources to LGBTQ+ older people and their caregivers. SAGE also advocates for public policy changes that address the needs of LGBTQ+ elders, including people aging with HIV.*



# Learning Objectives

Describe the unique challenges faced by older people living with HIV and the importance of providing comprehensive and tailored services that meet their needs.

Discuss current policies and practices that are in place to support this population.



Are you currently  
serving older  
people with HIV?

*If yes, in what ways?*

# People Aging with HIV

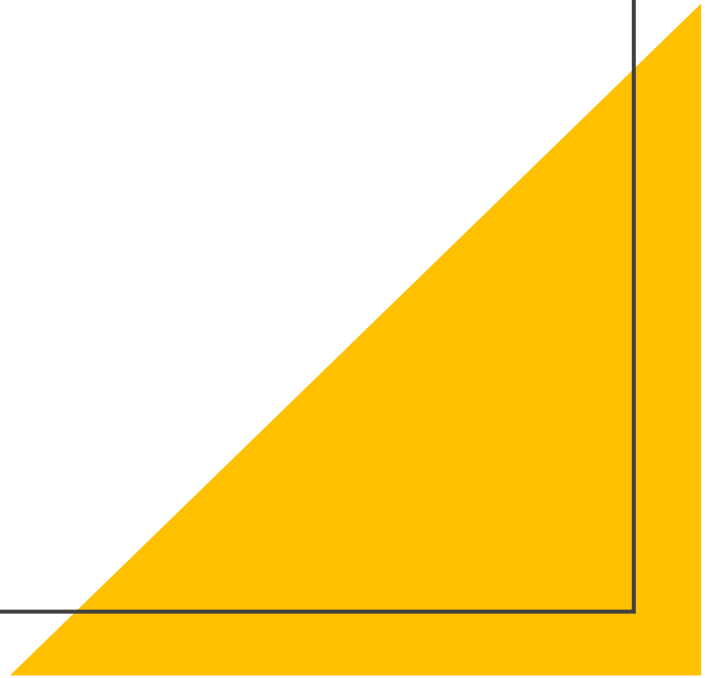
- People living with HIV who are 50 years and older
- People younger than 50:
  - Who are living with HIV since before effective treatments (before 1996)
  - Who are living with HIV for 10 years or more but since effective treatment (1996 and after)
  - Who have been living with HIV since their birth
- Many people aging with HIV have been living with HIV through different stages in their lives
- Ongoing need to understand the relationship between HIV and aging

Source: The Well Project and The Reunion Project

## Quiz Time!

By 2030, up to  
\_\_\_\_ % of people  
with HIV will be  
over the age of  
50.

1. 25%
2. 45%
3. 53%
4. 70%
5. 80%



# Older People Living with HIV



- In 2021, persons 50 years and older accounted for over 53% of all people living with HIV in the United States.
- In 2021, persons 50 years and older accounted for 16.4% of all HIV diagnoses among persons aged  $\geq 13$  years .
- Source: [Volume 34 | HIV Surveillance | Reports | Resource Library | HIV/AIDS | CDC](#)

# Older People Living with HIV

**BY 2030, UP TO  
70% OF PEOPLE  
WITH HIV WILL BE  
OVER THE AGE OF 50.**



HIVAGE™  
POSITIVELY

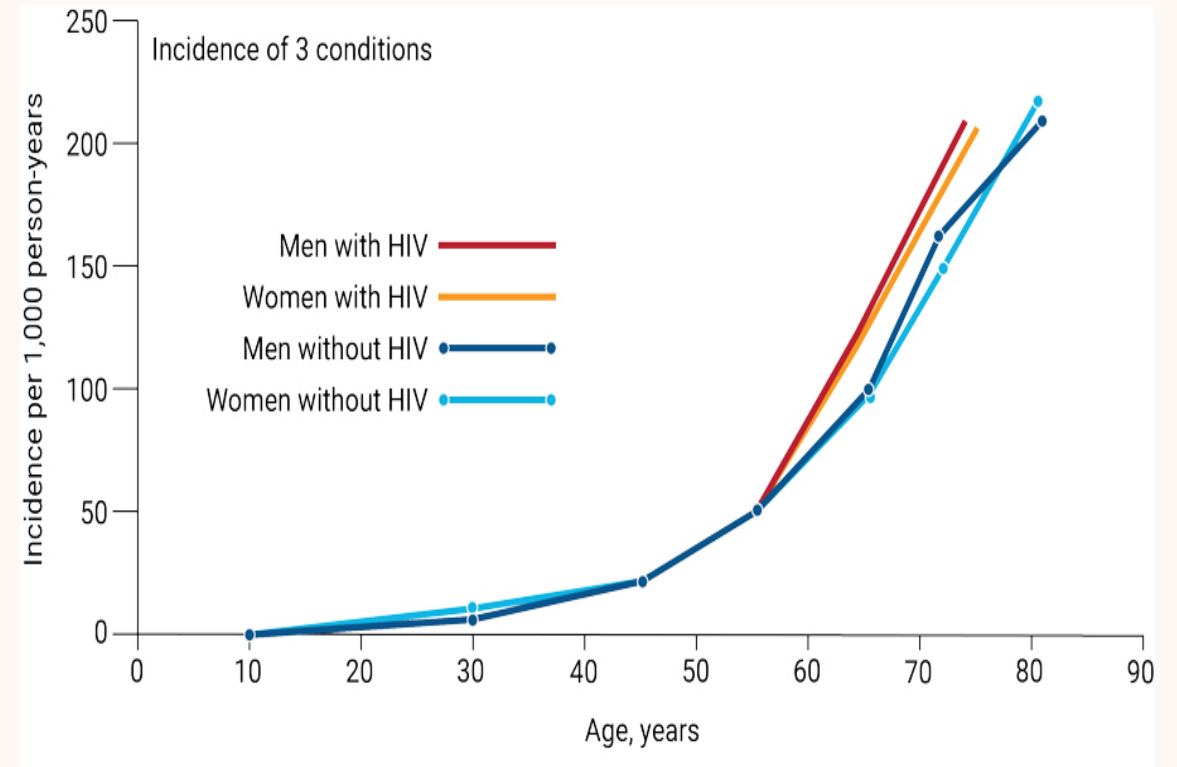
 GILEAD

Image source: [HIV Age Positively | Gilead](#)



# Impact of Aging on People Living with HIV

- HIV may accelerate the aging process
  - Effects of chronic inflammation
- HIV may increase on-set of age-related health conditions and risk for other chronic health conditions
  - Multiple co-morbidities and polypharmacy issues



• Image source: [HIV with a touch of gray - IAVI](#)



## Impact of Aging on People Living with HIV

Many of the medical problems now  
faced by people living with HIV  
have more to do with aging than  
with HIV-related illnesses.

Source: [Aging and HIV | The Well Project](#)

Image source: <https://www.pbs.org/newshour/health/long-term-survivors-of-hiv-aids-reflect-on-what-theyve-witnessed-and-endured>

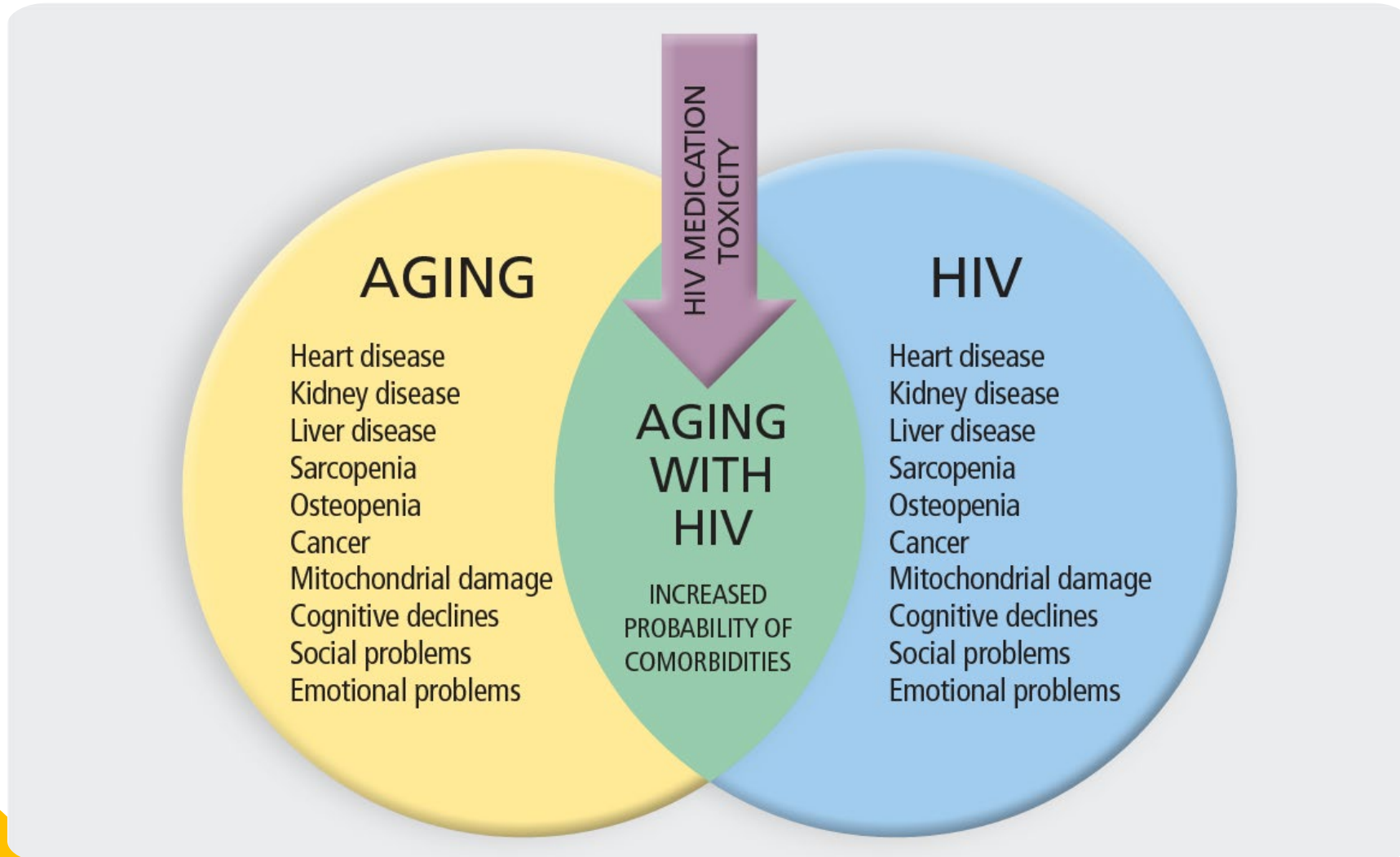


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## Medical and Health Considerations

- Screenings for PLWH for age-related comorbidities need to start earlier than for people who are not living with HIV.
  - Research shows that [PLWH are diagnosed with age-related comorbidities unrelated to HIV at an earlier age](#).
  - In most parts of the country, morbidity and mortality among individuals with HIV are now largely attributed to age-related non-AIDS comorbidities, such as cardiovascular, kidney, liver, and bone disease as well as cancer and neurocognitive impairment
- For the individual aging with HIV, greater longevity may be accompanied by early comorbidity onset. In addition to a potentially higher likelihood of feeling unwell compared with individuals without comorbidities (and for a longer time), there may be a need for a greater number of medications, clinic appointments, and hospitalizations.
- An older PLWH is likely to have many more health needs than one clinician can provide care. Care coordination will be key. Include social workers, case managers, and programs with peer workers!
- The drugs used to treat HIV may also contribute to the aging-related health conditions seen in people living with HIV. Although the HIV drugs used now are more effective and less toxic than drugs used in earlier times, they still may have long-term effects that we do not yet fully understand.

# HIV and Aging





# Helpful Documents

Addressing the Needs of Older Patients in HIV Care  
(New York State):

<https://www.hivguidelines.org/guideline/hiv-aging/?mycollection=hiv-care>

Care of People Aging with HIV: Northeast/Caribbean  
AETC Toolkit:

<https://acrobat.adobe.com/link/track?uri=urn%3Aaiid%3Aascds%3AUS%3A1a0240e1-1992-4442-91c7-bcf6a478bf1c&viewer%21megaVerb=group-discover>

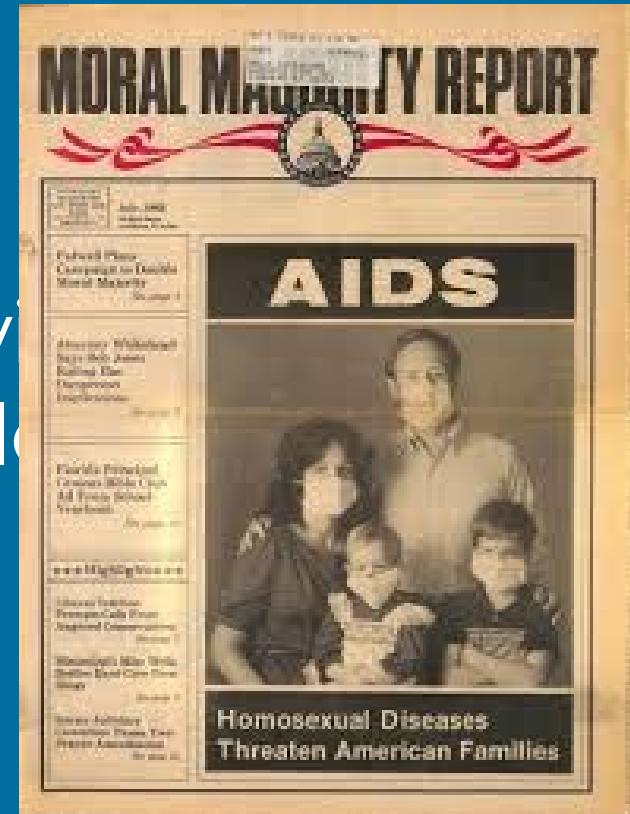
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# Psychosocial Considerations

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# Public Reactions to AIDS by Herek and Glunt

November 1988, American  
Psychologist



Coined the term “AIDS-related stigma.”

- Intense negative public reactions to person presumed to have HIV.
- Stigma is a mark of shame or discredit—individual, institutional policies that impose hardships on particular individuals or groups.



# People with HIV received the message loud and clear

- 1986 Op/Ed piece in the *New York Times*, William F Buckley Jr., proposed that “everyone detected with AIDS should be tattooed in the upper forearm, to protect common-needle users, and on the buttocks, to prevent the victimization of other homosexuals.”
- 1987 A mail carrier in White Plains, New York refused to deliver mail to an AIDS Task Force office for two weeks because he feared catching the disease.
- In Florida, three brothers with HIV. Their barber refused to cut their hair, the family minister suggested they stay away from Sunday church services, and eventually the family house was burned down.



# Today

Discrimination against people living with HIV is unfortunately common, and can manifest in many ways.

For example, an older person living with HIV may be denied employment or housing because of their status, or may face bullying or harassment from others in their community.

Blaming them for having HIV: must have done something wrong to contract the virus.

This can lead to people blaming an older person for their HIV status, spreading rumors about their character, or not including them.

WHAT DOES **HIV** STIGMA  
LOOK LIKE?



**STIGMA**



ISOLATING A PERSON OF THE SOCIETY  
WHO IS **HIV POSITIVE**

COMMUNITIES MAKES THE **DIFFERENCE**

**#endHIV**

## What is the impact on Older People with HIV?


“AIDS Survivor Syndrome” is used to describe the constellation of physical, psychological and emotional symptoms that a person (either HIV-negative or HIV-positive) may experience after living through intense grief and trauma during the years of the AIDS epidemic and after.

Symptoms may include: depression, uncertainty about the future, suicidality, feelings of panic from growing older, social isolation and social withdrawal, survivor’s guilt, and more.

Sometimes compared to Post-Traumatic Stress Disorder.



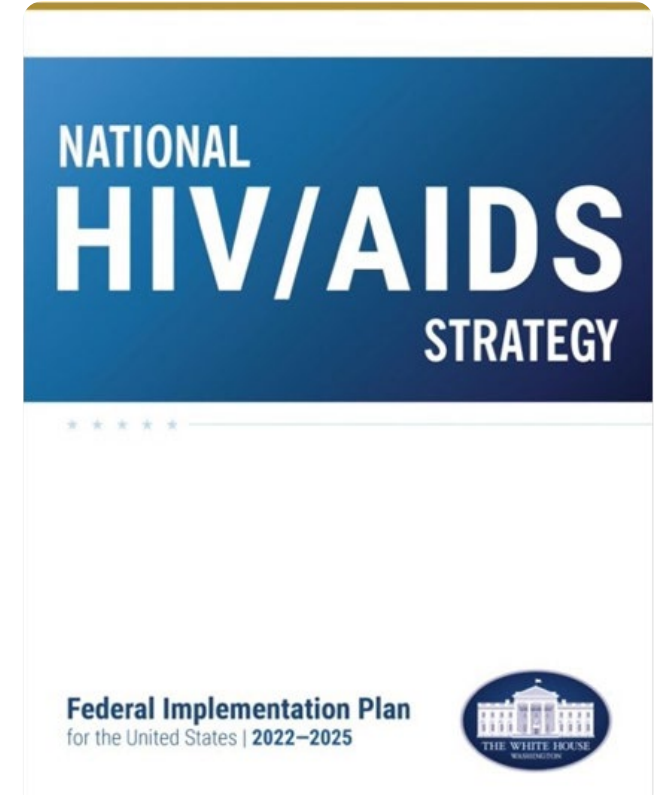
## Challenges faced by older people with HIV

- Difficulties in accessing and managing comprehensive and integrated health care
  - Need for mental health programs and substance and alcohol use treatment programs
  - Need for housing, food and nutrition, employment, and other socioeconomic support services
  - Need for long-term care
  - Need for programs that address loneliness and social isolation
  - Need to dismantle stigma and discrimination
- 

# Quality of life for older people with HIV

## Quality of life indicators:

- Self-rated physical health
- Need for mental/emotional health services
- Need for food and other subsistence services
- Employment status
- Access to stable housing





## Support for Older People with HIV

- Offer support and create programs for people aging with HIV: Counselors, peer mentors, or support groups can provide support, help with connections to activities and build community and reduce isolation and loneliness
- Provide opportunities to tell stories. Speaking truth is part of healing.
- Invite to have a seat at the table. Experts in living a long life with HIV, .....and must be part of organizational and policy decisions that impact their lives. Do you have a community advisory board? Invite them to be on it!
- Commemorate June 5, National HIV Long-Term Survivors Awareness Day (NHLTSAD). Not just an awareness day, but a call to action to keep needs and demands of HIV LTS front and center in the HIV community
- September 18<sup>th</sup> is National HIV/Aging Awareness Day
- Advocate for policy that supports people aging with HIV!



*"Ours is not a movement simply about nostalgia, pain and grief. It is also a testament to the resilience of the human spirit, to humans who rolled up their sleeves and refused to accept our death sentences."*

– From "A Vision of Our Future: HIV Long-Term Survivors Declaration ," by Let's Kick ASS



More  
**resilient** services  
for better coverage



**#ResilientHIVservices**

## Resources

- SAGE: <https://www.sageusa.org/>
- The Reunion Project: <https://www.reunionproject.net>
- Let's Kick ASS: <https://letskickass.hiv/>
- The Graying of AIDS: <https://agrayingpandemic.org/>
- Ryan White Programs: <https://ryanwhite.hrsa.gov/hiv-care/services>
- HOPWA: [https://www.hud.gov/program\\_offices/comm\\_planning/hopwa](https://www.hud.gov/program_offices/comm_planning/hopwa)
- The Well Project: <https://www.thewellproject.org/get-connected>
- US PLHIV Caucus: <https://www.hivcaucus.org/>



# ***LGBTQ+ and HIV Long-Term Care Bill of Rights***

- **Updates state/local law.**
- **Protects people from discrimination on the basis of sexual orientation, gender identity, and HIV status in long-term care settings.**
- **Mandates LGBTQ+ and HIV cultural competency training for staff.**

**Example: Make it illegal for a LTC facility to deny admission based on their SOGI or HIV status.**



# 6 Nursing Homes Accused of HIV Discrimination

*The facilities allegedly refused to accept a client because of his HIV status, according to the ACLU.*

[press release](#).



- When Courtney Shelor was looking for a nursing home in Nebraska to care for her father, John Shelor, six facilities refused to accept him because he was living with HIV, she says.
- Writing on her behalf, the American Civil Liberties Union (ACLU) of Nebraska sent letters to the nursing homes, warning them about the potential consequences of their actions and offering solutions. [release](#).

sage  
LOOKING AHEAD



# Resources



## LGBTQ+/HIV Long-Term Care Bill of Rights Toolkit

### What is an LGBTQ+/HIV Long-Term Care Bill of Rights?

An LGBTQ+/HIV Long-Term Care Bill of Rights (LTC BOR) protects people from discrimination on the basis of sexual orientation, gender identity (GID), and HIV status in long-term care settings. For example, a LTC BOR may make it illegal for a long-term care facility or its staff to deny admission to someone based on their SOGI or HIV status. It may make it illegal to refuse to acknowledge and/or treat a resident according to the resident's gender identity. Many other protections are often included as well.

### Why is this needed?

[Sage's 2015 report on the Field of LGBTQ+ Older Adults in Long-Term Care Facilities](#), a groundbreaking 2015 report by Justice in Aging, showed that only 22% of respondents thought that LGBTQ+ older people could be out to facility staff, 89% predicted that staff would discriminate against an out LGBTQ+ person, 87% thought that other residents would discriminate against that person, and 53% thought that staff would neglect or abuse the out LGBTQ+ person. 42% reported mistreatment, including verbal or physical harassment from other residents, refusal admission/acceptation/denial, and other types of mistreatment. The report contains accounts of staff refusing to use a transgender resident's proper name or pronoun, and refusing to provide even the most basic care. A 2014 SAGE Harris Poll study, [Out and Visible](#), revealed various challenges that LGBTQ+ older people in the United States face, including: profound concerns about physical decline, remaining independent, loneliness, and the loss of support systems; a fear of judgment and inferior care from healthcare providers, causing many not to

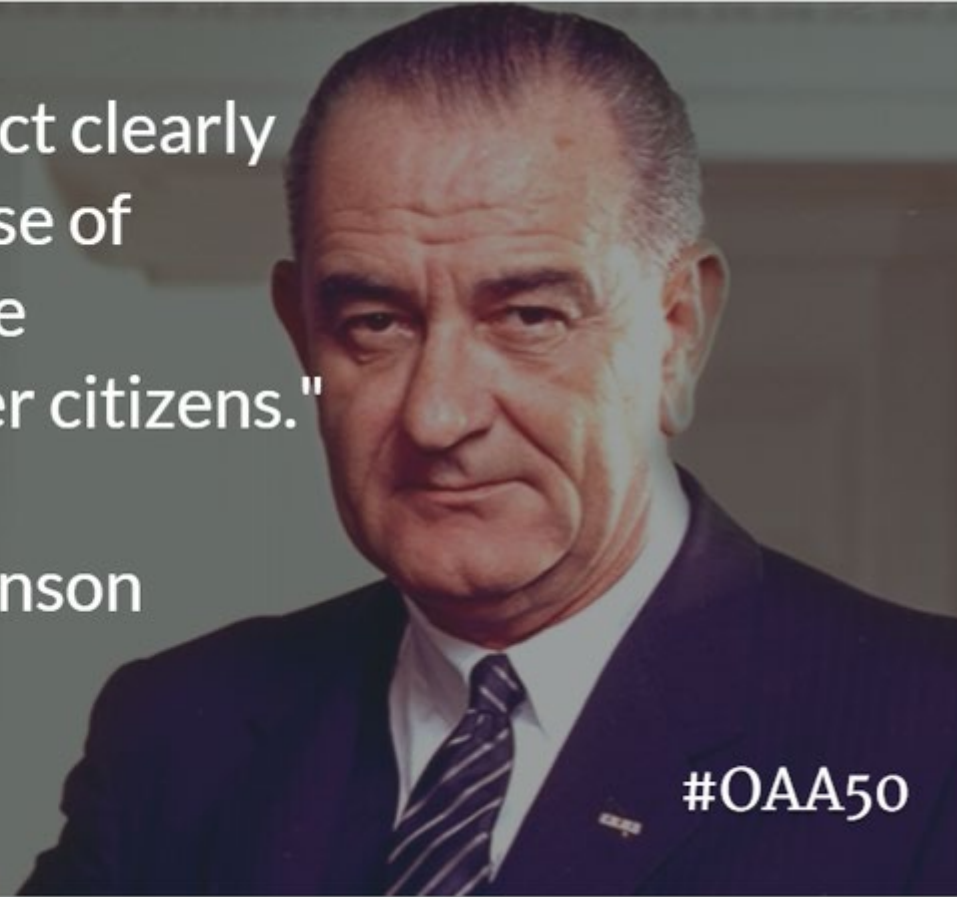
- **LGBTQ+ and HIV Long Term Care Bill of Right Toolkit:**
- <https://www.sageusa.org/wp-content/uploads/2021/09/ltc-bor-toolkit-hapac-v2-logos.pdf>

# OLDER AMERICANS ACT

"The Older Americans Act clearly affirms our Nation's sense of responsibility toward the well-being of all our older citizens."

President Lyndon B. Johnson  
July 14, 1965

#OAA50





Wednesday, August 30<sup>th</sup> 4:00-5:00 PM

ACL Track

Advancing Equity Through State Plans Responsive  
to the Needs of People Aging with HIV

## Questions/Discussion

1. In your state, community, or organization, what are (or could be) some challenges that older people living with HIV face?
2. What are some examples of local community resources that can support the health and well-being of older people living with HIV?
3. Do you have relationships with the HIV providers in your area, Ryan White, HOPWA, gerontologist that specialize in HIV?
4. How can you and your organization better support the unique needs of older people living with HIV?
5. What are some policy solutions that could improve the lives of older people living with HIV, such as better access to healthcare or programs to reduce isolation and loneliness?
6. How can we better educate the public about the experiences of older people living with HIV, and combat stigma and discrimination?
7. What role can peer support and community engagement play in promoting resilience among older people living with HIV?
8. What are some examples of successful interventions that have supported the health and well-being of **older people**, and how can we build on these successes to provide care and services for **older people living with HIV**?

# Thank you!

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