



## Policy Agenda Outline

HAPAC aims to ensure that the needs of older people living with HIV are addressed through federal, state, and local policy. HAPAC is working at the federal level, both administratively and legislatively, to advance HIV-inclusive aging policies. HAPAC has also chosen three states and Puerto Rico, where we are working to advance the interests of older people living HIV through policy change. This is where we are focusing our efforts.

### Federal Government

#### Health Resources and Services Administration (HRSA)

HRSA is responsible for administering the Ryan White HIV/AIDS Program. According to [their website](#).

The Health Resources and Services Administration's (HRSA) Ryan White HIV/AIDS Program provides a comprehensive system of HIV primary medical care, essential support services, and medications for low-income people with HIV. The program funds grants to states, cities, counties, and local community-based organizations to provide care and treatment services to people with HIV to improve health outcomes and reduce HIV transmission among hard-to-reach populations.

More than half of people with diagnosed HIV in the United States receive services through the Ryan White HIV/AIDS Program each year. That means more than half a million people received services through the program.

HRSA's HIV/AIDS bureau (HAB) is therefore a key federal partner in ensuring that older people living with HIV are getting the critical services and supports that they need.

A subset of the coalition has been speaking and advocating before policy makers with HRSA's HIV/AIDS Bureau. The coalition met with HRSA in late October 2020, including Dr. Laura Cheever, Associate Administrator for HAB, and we shared a laundry list of the challenges facing older people living and at risk for HIV. We have engaged with HRSA on a number of occasions following that meeting.

Our agenda includes the following:

- **Integration of Care:** How does HAB ensure seamless care for older PLWH with multiple comorbidities in lower resource states?
- **Mental/Behavioral Health:** Older PLWH have high rates of depression and social isolation, yet many struggle to access mental health care due to insurance payment issues. Many mental health providers don't accept Medicaid or even private insurance due to low reimbursement or delays. On top of all of that, there's lack of capacity in the behavioral health care system. What is HAB doing to address these challenges?
- **HCBS/ACL:** How are home and community-based services preparing to care for older PLWH? What kinds of collaborations does HAB engage in with ACL/AOA?
- **Isolation:** Isolation is of course a challenge for many older people, more so for older PLWH, and a particularly significant challenge for our older HIV+ gay male and trans female patients – we need to figure out ways to break that isolation. Many providers have shifted to telehealth in recent months, and this has definitely helped reduce isolation for some patients. Could ASOs obtain support thru Part A/B/SPNS to leverage technology in ways similar to how health centers and Part C clinics have been able to this? Related to this, how can we ensure that low income elders have access to the internet and are not isolated due to the digital divide?
- **Data:** We are glad that HAB collects and reports data on transgender patients. Why not collect and report data on sexual orientation identity of clients? Mode of transmission data (behavior at a point in time, often decades ago) is not the same thing. That data is probably very old for many older patients. Sexual orientation identity can change across the life course. Since two thirds of new diagnoses are among gay and bisexual men and other MSM, this is important to know.
- **Quality of Life:** How do we ensure that older PLWH have a high quality of life? How do we ensure that they can die with dignity?

- **Dental/Vision:** Medicare doesn't cover dental, so we need continued Part F support. Part F doesn't cover dentures. We need continued HDAP funding across the states, especially since Medicare patients cannot tap into drug manufacturer copay assistance cards. Do you have any data indicating that PLWH are disproportionately affected by dental and vision issues?
- **ACA:** Can you share what HRSA and Ryan White is planning to do in the year ahead to meet the needs of PLWH if the ACA is weakened or struck down by the Supreme Court?

In December 2020, SAGE worked with Sean Cahill at Fenway Health to send a letter on behalf of Fenway and HAPAC to HRSA to request the collection of sexual orientation data in the Ryan White program. Aaron has been in conversation with HRSA about how to more effectively engage with the Administration for Community Living. Aaron has also spoken with ACL about its goal of standing up a committee focused on HIV/aging issues and he has offered the committee the opportunity to meet with HAPAC members.

## Congress

We are working closely with the office of Rep. Suzanne Bonamici and the Congressional LGBTQ+Q+ Equality Caucus to introduce a comprehensive LGBTQ+/HIV aging bill in 2021. We hope that it will include some of the following:

### Greatest Social Need

- Amend the Older Americans Act to designate LGBTQ+ older people and older people living with HIV as greatest social needs populations.

### National LGBTQ+ Long Term Care Bill of Rights

- Bar [discrimination](#) on the basis of sexual orientation, gender identity, and HIV status in LTC settings.

### Cultural Competency Training Requirement

- Require all recipients of federal funding who currently serve older people (all aging providers etc. Medicare/Medicaid-funded facilities, HCBS) to satisfy a [cultural competency training requirement](#).

- Every staff person at any HCBS and any LTC setting that receives federal dollars and/or over which the federal government has any regulatory control, shall be subject to 1.5 hours of annual LGBTQ+ aging competency training by an agency deemed to have expertise in the area.

## Veterans

- Create an [advisory committee](#) to advise the Veterans Administration on how to best serve those who served under 10 USC 654 ("Don't Ask, Don't Tell"), the prior regulatory ban, and on-going policies that discriminate against transgender service members.
- Create a Center for LGBTQ+ Veterans at the Veterans Administration, modeled on the [Center for Women Veterans](#), to provide resources and support to those who faced discrimination under 10 USC 654 ("Don't Ask, Don't Tell"), the prior regulatory ban, and on-going policies that discriminate against transgender service members.
- Provide full GI Bill benefits to anyone who would have been eligible but for their ability to serve being cut-short because of 10 USC 654 ("Don't Ask, Don't Tell"), the prior regulatory ban, and on-going policies that discriminate against transgender service members.
- Create presumptive [mental health service-connected disability benefits](#) for any LGBTQ+ service member who served under 10 USC 654 ("Don't Ask, Don't Tell"), the prior regulatory ban, and on-going policies that discriminate against transgender service members and for anyone discharged under 10 USC 654 ("Don't Ask, Don't Tell"), the prior regulatory ban, and on-going policies that discriminate against transgender service members. LGBTQ+ service member would be defined as anyone who made a statement to anyone at any time that they were gay, or words to that effect, touched someone of the same-sex for sexual gratification, and/or married or attempted to marry someone of the same sex.

## HIV/Aging

- Require Medicare to cover [HIV tests](#) for all those 65+, regardless of risk factors.
- Create an HHS interagency task force on HIV and Aging (modeled on HHS's [Pain Management Best Practices Inter-Agency Task Force](#), to: to propose updates to best

practices and issue recommendations that address gaps in meeting the needs of older people living with and at risk for HIV; develop a targeted and coordinated cross-division research effort (specifically, research on psychosocial issues including non-medical supportive services, for at-risk older people living with HIV); develop and implement targeted prevention and treatment messaging for older people at risk for HIV; encourage cross-training on HIV/aging for HIV providers and gerontologists; and mandate access to universal adult HIV testing for people of all ages regardless of risk category.

- Lower the age at which older people living with HIV can access OAA programs to 45, similar to the bipartisan [Younger-Onset Alzheimer's Disease Act](#), key provisions of which were included in the most recent reauthorization of the OAA.

## Housing

- Under its Equal Access Rule and through its Fair Housing Initiatives Program (FHIP), require HUD to fund organizations and projects focused on promoting awareness and assistance regarding fair housing and equal opportunity among LGBTQ+ older people. Require HUD to study the impact and effectiveness of the Equal Access Rule on LGBTQ+ people in aging and long-term care settings, which includes evaluating current data on fair housing complaints based on sex and gender nonconformity.
- Require HUD to update all surveys that currently ask demographic data to include questions on sexual orientation and gender identity/transgender status. All of these studies should employ methodologies that ensure that sample sizes of LGBTQ+ older people are large enough for statistical analysis. Additionally, require testing on the prevalence of housing discrimination against LGBTQ+ older people. Finally, require HUD to survey state and local human rights agencies and other relevant entities that currently collect data on sexual orientation and gender identity to assess housing barriers facing LGBTQ+ people.
- Require HUD to require its grantees and recipients of HUD-insured loans and loan guarantees to be culturally competent on LGBTQ+ older adults through an approach that includes ongoing training, tools and best practices. Require HUD to encourage these entities to work with LGBTQ+ stakeholders in their communities, as well as develop programming that improves their LGBTQ+ cultural competence and better engages LGBTQ+ communities.

- Through the Low Income Housing Tax Credit Program (LIHTC), require the U.S. Department of the Treasury—with HUD’s involvement—to incentivize local housing and community development agencies to build LGBTQ+-friendly affordable senior housing developments in various parts of the country. Require HUD to direct state housing finance agencies nationwide to establish LGBTQ+-friendly affordable senior housing projects as housing priorities in their state Qualified Allocation Plans under the LIHTC Program.
- Require HUD to take appropriate steps to assess and monitor the extent to which grant recipients under Section 202 are complying with the LGBTQ+ protections outlined in the Equal Access Rule. Require HUD to ensure that any future efforts to collect data through a Section 202 national reporting system include questions on sexual orientation and gender identity/transgender status.
- Condition federal grants for senior housing construction on enacting non-discrimination protections and (where states are grantees) the uniform guardianship act.
- Authorize funding to promote the building-of and support for LGBTQ+-friendly, older adult, low income housing.

### **Families of Choice**

- Require ACL to review all regulations and policies that reference “families” and ensure that the definition of family in all circumstances recognizes families of choice, as defined in the [FAMILY Act](#).
- Extend Medicaid spousal impoverishment protections to families of choice.

### **Data collection**

- Require ACL to include sexual orientation and gender identity (SOGI) questions in all [data](#) collection instruments that already collect demographic data. Require ACL to adopt best practices for SOGI data collection, including using separate and independent questions for sexual orientation and gender identity and using the expert-advised two-step question for gender identity. Model on [H.R.3273 - LGBTQ+ Data Inclusion Act](#).

- Require the CDC and related federal agencies to collect SOGI data in all health surveillance programs (including when collecting data on COVID-19) whenever other demographic data is collected.

### **Non-Discrimination**

- Bar discrimination on the basis of sexual orientation and gender identity in all ACL funded programs, services, and supports (including beneficiaries of aging programs, as well as the employees of the entities providing services).
- Ensure partner/visitor recognition and nondiscrimination in all long-term care facilities and service providers who receive any federal financial assistance

### **Social Security**

- As outlined in the [Anthony Gonzales Equality for Survivors \(AGES\) Act](#) (H.R. # TBD, formerly H.R. 2247):
  - o Establish an alternative method for meeting the nine-month marriage requirement for certain survivors to receive benefits under the Old Age, Survivors, and Disability Insurance benefits program.
  - o Apply to marriages that would not have been recognized by federal law before June 26, 2013 (the date upon which the Supreme Court ruled that same-sex couples are entitled to federal benefits).
- Build on the AGES act, which only covers people who were able to get married (but weren't in the marriage long enough to qualify for benefits). There are others who were never married in the eyes of the federal government (for example, same-sex couples who married in Massachusetts and the husband/wife died before Obergefell), so even the AGES act would not provide for SSA to recognize their marriage. These individuals should also qualify for the SSA benefits to which they would otherwise be entitled but for the unconstitutional and discriminatory laws in place at the time they got married and their spouse died.

- Update the Social Security Act to include recognition of long-term partners or other family member not based on marriage, like the mutually dependent partner approach starting on page 13 of [this document](#) on Medicaid Spousal Impoverishment.

### **Commission on Discrimination**

- Establish a commission to study the moral imperative of making whole those that the federal government fired from the civil service and military because of their sexual orientation and/or gender identity.

### **ACL**

- Encourage ACL to pilot a home-visitation program for older LGBTQ+ people and PLHIV living alone.

### **Transgender Older People**

- Create model policy for amending death certificates akin to the birth certificates provision in the model state vital statistics act.
- Authorize grants for civil legal agencies to assist with end-of-life issues, including will-writing, and for state funeral home regulatory agencies to draft and implement state regulations to protect the trans bereaved.

### **Hunger**

- Pilot a program to close the gaps for LGBTQ+ older people who are not accessing Title III B nutrition programs.
- Encourage ACL to work with USDA to engage in a targeted outreach and enrollment project focused on LGBTQ+ older people.

## **Louisiana, Puerto Rico, Georgia, and Florida**

### **Louisiana**

In Louisiana, we are working with Jim Meadows, who runs SAGE New Orleans. In speaking with advocates on the ground, he learned that older people living with HIV hope to have more a say in the local Ryan White Planning Councils. As a first step in getting to that goal, SAGE brought on Amy Killelea to write a toolkit for HAPAC on how older people living with HIV can serve on Ryan White Planning Councils. She most recently headed-up policy work and Ryan White technical assistance at the National Alliance of State and Territorial AIDS Directors (NASTAD).

The toolkit covers the following: what is Ryan White and what are its planning councils; why is it important/beneficial to join them/be at the table; how does one join them; once one joins a planning council, how can one advocate for aging-inclusive programs/policies; what are some examples of aging-inclusive policies/programs a planning council could implement; and what are ways to influence/impact the planning council if one is unable to join a planning council. The toolkit also contains a glossary of terms associated with RW and the planning councils.

While the initial focus of the toolkit was RW planning councils in Louisiana, Amy crafted the toolkit in such a way that it will be easily adaptable to other states/jurisdictions.

The toolkit contains a sufficient amount of substantive information and at the same time be approachable to someone not well versed in HIV policy.

The toolkit will be completed by August 2021, after which we hope to launch a campaign to raise awareness about the toolkit and get it in the hands of older people living with HIV throughout Louisiana.

### **Puerto Rico**

In Puerto Rico, SAGE is working closely with HAPAC members Moises Agosto, Ricardo Jimenez, and Jesus Ramirez-Valles. We are also working with Wilfred Labiosa, Executive Director of WAVES AHEAD, and leader of SAGE's Puerto Rico affiliate. In consulting with older people living with HIV and those serving them in Puerto Rico, they decided that the most important first step to take is a needs assessment of older people living with HIV. To that end, Wilfred commissioned a proposal from John Snow Inc., a HRSA contractor, to evaluate gaps and opportunities for change. As Wilfred wrote, in part, in his letter to SAGE:

“Some months ago, we received a call from members of this Action Coalition asking how you could help the LGBT+ older adults living with HIV/AIDS in Puerto Rico. I had some conversations in regards to this topic but we realized that there isn’t a source of information (data) to inform policy action on behalf of this population living in the island. After holding some meetings with key leadership in the island, as well as gay men living with HIV, we realized that the first thing we should do is to conduct a needs assessment with this population. We propose to conduct a needs assessment, across the island and across individuals receiving services from a Ryan White PART A, B and C provider, as well as those out of services. We would like to hire an entity to lead these efforts and work collaboratively with community-based organizations, medical entities, and community leaders, in a three-month period of time. We have met for few months, reviewed and discussed the data available and none include the question in regards to sexual orientation and gender identity, LGBT+. We found that there is a profile of those living with HIV/AIDS in the island, up to 2018. There is some data in-regards to client satisfaction surveys of Part A, B and C but nothing about this population. We would like to conduct this needs assessment focusing in four main topics: 1) Access to Clinical Care; 2) Access to Appropriate Housing; 3) Access to mental health services and supports; and 4) Access to technology and education regarding technology, and demographical information. We requested proposals from entities and have decided on John Snow, Inc.”

SAGE and AIDS United have committed, in-part, to funding the needs assessment. WAVES AHEAD has been moving forward on the needs assessment during 2021.

## **Georgia**

In Georgia, SAGE is working with HAPAC member Malcolm Reid, Program Manager THRIVE SS Inc./Silver Linings Project. Malcolm has been working with THRIVE SS to support black men living with HIV for the last 4 years. He is a co-author and Program Manager of the Silver Lining Project; a program to support and advocate for black gay men over the age of 50, living with HIV. In consulting with community members, Malcom has found that there is a desire to make it easier for older people living with HIV to access telehealth, especially during the COVID-19 pandemic. Counterintuitively, the State of Georgia does not allow individuals to access telehealth from their homes. Malcom has been exploring avenues for change and how HAPAC members can help advance either administrative or legislative policy change that will allow older people

living with HIV and others to access the care they need. He is also exploring a needs assessment, to be modeled on the successful work of WAVES AHEAD.

## Florida

SAGE and Equality Florida hope to introduce an LGBTQ+/HIV Long Term Care Bill of Rights at the state level or to partner with localities to do the same. SAGE has shared our model LTC Bills of Rights language with Equality Florida, which is navigating Florida's challenging political environment – including the localities who might be more receptive to change. Given Florida's challenging political environment, we and Equality Florida look to the possible state-wide legislation as a conversation-starter, to set the bar for what might be done in the state if the political winds change, and as an opportunity to educate policy makers across Florida on the need for non-discrimination protections in long term care settings. The expectation is that localities will see the legislation and be inspired to make change where they live. We will proactively work with those policy makers in key cities and counties to advance more localized LTC Bills of Rights, which would protect people from discrimination on the basis of sexual orientation, gender identity, and HIV status in LTC settings, and lay a foundation for state-wide change.