**SAGE’s (Services and Advocacy for GLBT Elders)**

**Policy Recommendations for the**

**2015 White House Conference on Aging**

**A Growing Momentum to Recognize and Address the Unique Barriers to Successful Aging Faced by Lesbian, Gay, Bisexual, and Transgender (LGBT) Older Adults and Older Adults with HIV**

As the timeline below illustrates, the past few years have witnessed a growing momentum by the White House, the Administration for Community Living (ACL), Congress, and the broader aging network to recognize and address the unique barriers to successful aging faced by LGBT older adults and older adults with HIV.

In March 2010, ACL’s Administration on Aging (AoA) created the National Resource Center on LGBT Aging, the first-ever, federally-funded resource center dedicated to providing information, technical assistance, and training to the aging network, LGBT-serving organizations, and LGBT and HIV positive older adults themselves, on how to address and meet the unique needs of these growing populations.

In April 2011, the Leadership Council of Aging Organizations (LCAO) released its consensus recommendations for the reauthorization of the Older Americans Act (OAA), including the critical recommendation to designate LGBT older adults and older adults with HIV as populations of *Greatest Social Need*. In a law that already focuses services and supports on those who are the most vulnerable, this action would emphasize the targeting of services and supports towards LGBT older adults and older adults with HIV.

Also in April 2011, the Department of Health and Human Services (HHS) made an important announcement. It said that states would be notified about their ability to offer same-sex spouses and partners the same spousal impoverishment protections that already existed for married different-sex couples. On June 10, 2011, the Centers for Medicare and Medicaid Services (CMS) wrote to state Medicaid Directors, explaining that they were now able to offer protections to same-sex couples with regard to lien imposition, lien and estate recovery, and transfer penalties.

In November 2011, the Congressional LGBT Equality Caucus hosted a briefing featuring, among other speakers, then Assistant Secretary for Aging, Kathy Greenlee, drawing attention on Capitol Hill to the policy challenges requisite to improving the lives of LGBT older adults.

In January 2012, Senator Bernie Sanders (I. VT), then Chairman of the Senate Subcommittee on Primary Health and Aging, announced that his proposed amendments to the OAA would include listing LGBT older adults and older adults with HIV as groups of *Greatest Social Need*. As the chair of this key subcommittee, and as a high-profile aging advocate, he put the *Greatest Social Need* designation front-and-center as the Senate moved towards reauthorization of this critical piece of legislation.

The White House itself has also recognized the growing importance of addressing the challenges faced by LGBT older adults. On May 7, 2012, SAGE and more than 160 aging advocates from across the country convened for the first-ever White House LGBT Conference on Aging, hosted in partnership with the University of Miami Center on Aging. Congresswoman Debbie Wasserman Schultz (D. FL. 20th), Administrator Kathy Greenlee, and Assistant Secretary for Housing Raphael Bostic delivered the morning’s keynote addresses, focusing on the importance of meeting the unique needs of this growing population.

In July 2012, ACL took a significant step in recognizing and addressing the pronounced needs faced by LGBT older adults. ACL released guidance empowering the aging network to immediately consider LGBT older adults a population of *Greatest Social Need*. This announcement paved the way for Area Agencies on Aging (AAAs) to target LGBT older adults in their programs and services.

On September 19, 2012, Senator Michael Bennet (D. Colorado) introduced the first-of-its-kind “LGBT Elder Americans Act of 2012,” a bill that would expand supports to LGBT older people through the OAA.  The bill included proposals for specifying LGBT elders as a population in *Greatest Social Need*, would require the collection of data on services provided to LGBT elders, and would permanently establish the National Resource Center on LGBT Aging.  Senator Sanders included Sen. Bennet’s language in his second, base, Democratic bill, which he introduced the same day.

In early 2013, the Centers for Disease Control and Prevention (CDC) took a significant step in raising awareness around the aging of the HIV epidemic. Advocates had been pushing the CDC to report surveillance data in five year increments across multiple risk categories for those 55+, to evidence the need for provider and consumer education, and because detailed data would be useful in tracking the epidemic’s course.  The CDC finally issued this data in February 2013, in a report entitled the “HIV Surveillance Report (Supplemental Report): Diagnoses of HIV Infection among Adults Aged 50 Years and Older in the United States and Dependent Areas, 2007–2010.” The CDC now provides data including ages: 50-54, 55-59, 60-64, 65-69, 70-74, 75-79, 80-84, 85+.  As referenced below, it is a step in the right direction.  But as we know, we won’t get good testing rates of older adults unless the CDC messages to older adults and their providers about the need for routine annual testing.

In the past few years, Congress has also shown a renewed focused on HIV and aging. On September 18, 2013,National HIV/Aging Awareness Day, the Senate Special Committee on Aging to hosted a National HIV/AIDS and Aging Awareness Day Staff Briefing, Reception, and Hearing on Capitol Hill. The events of the day highlighted the needs and challenges of older adults with and at risk for HIV. In particular, the discussion focused on federal AIDS policy and how investments in HIV and aging research, care, and programs would both improve and extend lives and save money.

Lest we forget the OAA reauthorization, by 2014, the process finally wended its way to the House of Representatives. On February 28th, 2014, Rep. Suzanne Bonamici (D. OR 1st) introduced the House, Democratic, OAA reauthorization bill.  Following Sen. Bennet’s lead, her bill included three key LGBT-inclusive priorities, including: (1) designating LGBT older adults as a group of *Greatest Social Need;* (2) data collection; and (3) permanently establishing the National Resource Center on LGBT Aging.

On June 24, 2014, ACL once again made a big announcement. It released an online learning tool, entitled, “Building Respect and Dignity for Lesbian, Gay, Bisexual and Transgender Older Americans in Long-Term Care.” The LGBT Training tool is housed on the ACL-funded National Resource Center on LGBT Aging website and has already proven to be an invaluable resource for staff in long term care facilities.

In June 2014, the White House twice highlighted the importance of recognizing the unique experiences of LGBT older adults. SAGE, StoryCorps and the White House co-hosted "Generations of Pride," an event held at the White House to honor the lives of LGBT older people and young people. And on June 30, 2014, the President specifically referenced the importance of reaching out to and addressing the needs of LGBT older adults: “We’ve got to keep on reaching out to LGBT Americans who are vulnerable and alone, and need our support –- whether it’s teenagers in rough situations to seniors who are struggling to find housing and care.”

**The Need and the Opportunity for Administrative Action in the Next Two Years**

Through their respective actions, the White House, ACL, Congress, and the aging network, have all recognized what the available research shows - that LGBT older adults have fewer sources of support compared to heterosexual individuals and therefore suffer higher poverty rates and experience poor health and health access. As a result of facing a lifetime of stigma and discrimination, many remain socially isolated (twice as likely to be single and living alone and four times less like to have children than their heterosexual counterparts); many lack access to culturally competent health care; many have lower incomes and fewer sources of government supports than their heterosexual counterparts; and many struggle to find secure and affordable housing—a reality that places them at a significant disadvantage at a vulnerable point in their lives. In fact, this population is growing. As the number of Americans age 65 and older surges over the next few decades, the number of LGBT older adults is estimated to double to 3 million, by the most conservative estimates, by 2030.

These same entities and institutions have also recognized that there is a growing population of older adults with HIV. When this conference is held in 2015, one-in-two people who are HIV positive will be over the age of 50. By 2020, more than 70 percent of Americans with HIV are expected to be age 50 and older. According to the Centers for Disease Control and Prevention (CDC), research from 2013 shows that people age 50 and older represent one in six new HIV diagnoses. This research also shows that about half of this population is concurrently diagnosed with AIDS, meaning that their HIV disease has advanced to a stage where the health complications and treatment interventions are more severe and complicated. It also means that many older people were not tested or diagnosed early. This may be attributed to health providers mistakenly assuming that older people are not sexually active; older people not seeking HIV tests for fear of discrimination; and the CDC recommending routine testing for people only up to age 65. Unfortunately, few national or regional HIV prevention campaigns explicitly target older people.

In the face of these challenges and the unprecedented growth of these underserved populations, we believe the White House Conference on Aging presents a unique opportunity to capitalize on the momentum outlined above- to take the next, concrete, administrative actions that can begin to address the challenges faced by these populations – and to make impactful changes to better the lives of LGBT older adults and older adults with HIV.

Below, please find SAGE’s policy recommendations for the 2015 White House Conference on Aging. These policy proposals fit into the four themes of the conference: (1) retirement security; (2) healthy aging; (3) long term services and supports; and (4) elder justice. Should it be helpful, we would be pleased to provide you with a more detailed analysis/outline of how these administrative changes can be made.

**Specific Administrative Asks**

**Non-Discrimination, Cultural Competency, and Data Collection**

**Themes:** LTSS and Elder Justice. **Relevant agencies/entities:** White House andHHS/ACL

* **Non-Discrimination** 
  + Issue an Executive Order barring discrimination on the basis of sexual orientation and gender identity in nursing homes, long term care settings, and any entity that serves older adults and receives federal funds.
* **Cultural Competency**
  + Encourage State Units on Aging (SUAs) and Area Agencies on Aging (AAAs) to enter into new cooperative arrangements with organizations that serve LGBT individuals and require SUAs and AAAs to consider LGBT cultural competency in funding providers of services and supports.
  + Require SUAs and AAAs, and providers of services and supports, to take affirmative steps to participate in LGBT cultural competency trainings and establish LGBT-culturally competent practices and procedures.
  + Prioritize research and development grants for organizations working to improve the health, long-term care, and access to culturally responsive services for LGBT older adults.
* **Data Collection**
  + Report on the number of LGBT individuals reached through activities carried out under the Older Americans Act and the effectiveness of those activities in reaching LGBT older adults. Conduct studies and oversee data collection on the service needs of LGBT older adults. Require data collection and analysis on the effectiveness of the SUAs and AAAs in targeting services at LGBT older adults.
  + Develop appropriate protocols, demonstrations, tools, or guidance for use by SUAs and AAAs, to ensure successful implementation of data collection requirements.
  + Require long-term care ombudsmen to collect and analyze data relating to discrimination against LGBT older adults in long-term care settings. And require the Director of the State Long-Term Care Ombudsman Programs’ annual report to include the effectiveness of long term care ombudsman services in meeting the needs of LGBT individuals.

**Housing**

**Themes:** Housing, Retirement Security, and Healthy Aging.  **Relevant agencies:** HUD, Treasury, and Commerce

* **Data Collection, Surveys, and Research**
  + Update relevant surveys to include questions on sexual orientation and gender identity, and employ methodologies that ensure that sample sizes of LGBT older people are large enough for statistical analysis. HUD administers a range of studies related to housing that could benefit from questions on sexual orientation and gender identity, including but not limited to: the American Housing Survey (which studies a broad range of housing subjects); the Family Report (which tracks HUD-assistance housing programs, including the housing needs of special population groups); and the Family Options Study (which assesses how interventions support families experiencing homelessness).
  + More broadly, the federal government could prioritize the collection of data related to sexual orientation and gender identity in its population-based surveys, including the U.S. Census Bureau's various surveys (e.g., the American Community Survey, the National Decennial Census, and the Current Population Survey).
  + Engage in new research to continue testing the prevalence of housing discrimination against LGBT older people - in the rental market, in the sale of housing, in lending, and in the vast array of senior housing communities.
  + Study the impact and effectiveness of the Equal Access Rule on LGBT people in aging and long-term care settings, which includes evaluating current data on fair housing complaints based on sex and gender non-conformity, and specifically evaluating complaints in HUD’s TEAPOTS system to identity complaints based on gender non-conformity.
  + Survey state and local entities – such as state and local human rights agencies - that currently collect data on sexual orientation and gender identity, to discern the housing barriers facing LGBT people (as HUD did in advance of developing the Equal Access Rule), with a specific focus on older adults.
* **Cultural Competency**
  + Require grantees and recipients of HUD-insured loans and loan guarantees to be culturally competent on the needs of LGBT older adults through an approach that includes delivering ongoing training, tools and best practices.
  + Encourage these entities to work with LGBT stakeholders in their communities and to develop programming that improves their LGBT cultural competence and better engages LGBT communities.
  + Under the Equal Access Rule and through the Fair Housing Initiatives Program (FHIP), fund organizations and projects focused on promoting awareness and assistance with respect to fair housing and equal opportunity among LGBT older people.
* **Inclusive Affordable Housing for Older Adults**
  + Issue explicit guidance to grant recipients under HUD’s Section 202 program—as well as other applicable programs targeting older adults—that housing discrimination against LGBT people is unlawful under HUD’s Equal Access Rule.
  + Take appropriate steps to assess and monitor the extent to which grant recipients under Section 202 and other HUD programs are complying with the LGBT protections outlined in the Equal Access Rule.
  + Ensure that any future efforts to collect data through a Section 202 national reporting system include questions on sexual orientation and gender identity.
  + As HUD develops demonstrations related to enhancing the HUD 202 program and other demonstration programs - ensure that any further demonstrations comply with LGBT protections outlined in the Equal Access Rule.
* **Development of Affordable, LGBT-Friendly Older Adult Housing**
  + Through the Low Income Housing Tax Credit Program (LIHTC), the U.S. Department of the Treasury—with HUD’s involvement—could incentivize local housing and community development agencies to build LGBT-friendly, affordable senior housing developments in various parts of the country.

**HIV/AIDS**

**Themes:** Healthy Aging, Housing, and LTSS**. Relevant agencies:** HHS

* **Improve Care, Services and Supports for older Adults with HIV/AIDS**
  + HHS should issue treatment guidelines for the clinical care of older people with HIV, with specific attention to cultural and linguistically competent care when dealing with older people of color and LGBT elders.
  + HRSA-HAB should consider demonstration projects to address the specific needs of an aging epidemic, particularly in light of the well-documented comorbidities.
  + HRSA-HAB AETCs to be re-bid in 2015, should include HIV/aging-specific training/TA/CBA from all proposers in response to a rapidly aging epidemic, and require training of all providers, not just those in receipt of Ryan White money.
  + HHS OHAIDP should convene a meeting with SAMHSA, HRSA-HAB and others to ensure that SAMHSA’s very substantial resources are appropriately targeting the mental health and substance use services needs of an aging epidemic, not least a focus on depression.
  + DPC/ONAP/ACL should consider how to secure targeting of services and supports and data collection on HIV positive older adults under the Older Americans Act.
* **Improve Research** 
  + The National Institutes of Health (NIH) should support more research on HIV and aging, including research on women, LGBT people and various communities of color.
  + Research should look closely at differences within more marginalized and less studied subgroups of these populations (e.g. transgender people, Southeast Asian communities).
  + NIH should support research in the priority areas identified by the NIH Office of AIDS Research (OAR) Special Working Group on HIV and Aging, including but not limited to multi-morbidity management, behavioral health needs and caregiver support resources.
  + NIH should reconvene the NIH-OAR aging working group to assess progress on its recommendations since early 2012 and address research gaps, particularly with regard to older adults.
* **Improve Testing Rates among Older Adults**
  + The CDC should dedicate resources to prevention campaigns and interventions that target older people age 50 and older. To ensure that these campaigns reach older people of color and LGBT older people, these campaigns should place a specific emphasis on working with organizations that engage these populations to ensure cultural and linguistically competent messaging, representations, and implementation.
  + The CDC and the United States Preventative Services Task Force should re-examine their testing recommendations to encourage regular HIV testing among people older than 65, to increase “routine” testing of all older adults up through at least their early 70s, and disseminate the guidelines to ALL primary care providers. (CDC data suggests it is cost-effective to test all older adults at least up through their early-mid 70s, i.e., the prevalence rate is in excess of 0.1%).
  + HRSA-HAB should encourage Ryan White recipients to use testing resources to specifically target older adults by ensuring planning councils include such testing as a priority and contracts are secured with the organizations most able to reach these individuals.
  + HRSA-HAB AETCs should include training/TA/CBA to disseminate HIV testing best practices and approaches among ALL primary and other care providers with the aim of increasing routine testing among ALL older adults.
  + In a related vein, expand cultural competency training for testers and providers aimed at reducing homophobia, elder sex phobia, ageism, HIV fears/myths, etc. and thereby increase routine testing of ALL older adults.
  + Increase partnering across HIV services/testing networks, the aging network, and faith-based community organizations to improve testing rates among older adults.
  + With CDC and other support, such as the LGBT philanthropic community, develop and disseminate HIV testing/prevention/PrEP/PEP social messaging and marketing campaigns targeted at the most at-risk older adults.
  + Advocate among allies in the LGBT and HIV communities to increase HIV-related grants and advocacy from the LGBT philanthropic community to better address the needs of at-risk older adults.
  + Include White House Office of Faith-based and Neighborhood Partnerships in efforts to reduce homophobia and HIV fears/myths and increase HIV testing among older adults, including specific efforts with faith-based organizations.
* **Improve Data Collection**
  + The CDC should integrate its new five-year incremental data for people age 50-85 into its routine HIV surveillance reports on people age 49 and younger.
  + The CDC should provide data on HIV testing rates among older people, as well as the total number of HIV tests conducted annually among people age 50 and older. (As one example, data that shows the age at which HIV infection occurs, as opposed to when HIV is detected, would be particularly informative.)
  + The CDC should provide better data on AIDS-related morbidities and mortality rates, given the high rates of AIDS among older people. All of this data collection and reporting should include breakdowns by race, ethnicity, sexual orientation and gender identity to better capture the realities of older people of color and LGBT older people with HIV.