



DIVERSE
ELDERS
COALITION

Issue Brief

8 Policy Recommendations for Improving the Health & Wellness of Older Adults with HIV

From the first known cases of the HIV/AIDS epidemic in 1981 until the mid-1990s, most people diagnosed with HIV faced death within a few years, if not sooner. Yet with the advent of effective anti-retroviral treatments—and because of the extraordinary contributions of courageous advocates, scientists and clinicians—HIV has become a more manageable chronic illness, as evidenced by the increasing numbers of older people living and aging with HIV. Research estimates predict that 50 percent of people with HIV in the U.S. will be age 50+ by 2015—and by 2020, more than 70 percent of Americans with HIV are expected to 50+.

However, the successes of new treatments and increased longevity for people with HIV have brought new challenges to the proper prevention and care of older adults with HIV, many of whom are LGBT and people of color. Research continues to show that older people with HIV in their 50's and 60's have as many age-related comorbidities as people without HIV who are much older. The large-scale realities of aging with HIV are insufficiently studied and there exist few prevention campaigns, clinical guidelines, demonstration projects or training initiatives aimed at older adults with HIV, especially for older people of color and LGBT older adults. Moreover, older adults with HIV are often omitted from major legislation, policy initiatives and programs—from the White House Conference on Aging, to the Older Americans Act and the Ryan White CARE Act, to the Medicaid expansion, and more. Left unaddressed, generations of older adults with HIV will lack the supports they need to age in good health.

Recognizing that the HIV/AIDS epidemic has disproportionately affected communities of color and LGBT people since its beginning, the Diverse Elders Coalition and ACRIA (AIDS Community Research Initiative of America) offer eight policy recommendations that can dramatically improve the lives of older people with HIV.

The DEC is deeply grateful to the many experts who informed this report, including: Patrick Aitcheson, Diverse Elders Coalition; Mark Brennan-Ing, AIDS Community Research Initiative of America; Robert Espinoza, SAGE (Services and Advocacy for GLBT Elders); Bryan Pacheco, Diverse Elders Coalition; Aaron Tax, SAGE (Services and Advocacy for GLBT Elders); and Daniel Tietz, AIDS Community Research Initiative of America.

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1 PRIORITIZE HIV AND AGING AT THE 2015 WHITE HOUSE CONFERENCE ON AGING TO ENSURE THAT THE CONFERENCE'S RECOMMENDATIONS EMPHASIZE OLDER ADULTS WITH HIV, INCLUDING PEOPLE OF COLOR AND LGBT PEOPLE.

Since its inception, the White House Conference on Aging has been held every decade, offering an opportunity for communities around the country to reflect on the most pressing issues facing older Americans. The conference has historically sparked major legislative initiatives and shaped national aging policy for the ensuing decades. The upcoming 2015 White House Conference on Aging provides a key opportunity to address the contemporary issues facing older adults with HIV, many of whom are LGBT and people of color. Emphasizing these issues will ensure that the conference speaks to major demographic shifts in this country, including the growing number—and needs—of older people, people of color, LGBT older people and the first generation of people to age with HIV/AIDS.

RECOMMENDATIONS: The White House Conference on Aging should include tracks focused on the socio-economic needs of older adults with HIV, including LGBT elders and elders of color, as well as their many policy barriers. The various policy recommendations offered throughout this brief should be integrated into the official recommendations that emerge from the 2015 White House Conference on Aging.

WHY THIS MATTERS TO THE DIVERSE ELDERS COALITION: Half of all Americans diagnosed with HIV will be age 50 or older by 2015; that proportion will rise to more than 70 percent by 2020.¹ People of color are disproportionately affected by HIV/AIDS. Though African Americans represent approximately 12 percent of the U.S. population they accounted for an estimated 44 percent of new HIV infections in 2010.² Similarly, Latino people represent about 16 percent of the U.S. population but account for an estimated 21 percent of new HIV infections in 2010.³ Men who have sex with men (MSM) accounted for 79 percent of new HIV diagnoses in 2011.⁴

¹ *Older Americans: The changing face of HIV/AIDS in America*, of the Senate Special Committee on Aging, 113th Congress. 1 (2013) (testimony of Daniel Tietz).

² Centers for Disease Control and Prevention (CDC) (2013) *HIV in the United States: at a glance – fact sheet*. Retrieved from: <http://www.cdc.gov/hiv/statistics/basics/ataglance.html>

³ CDC (2014) *HIV among Latinos – fact sheet*. Retrieved from: <http://www.cdc.gov/hiv/risk/raciaethnic/hispaniclatinos/facts/index.html>

⁴ CDC (2013) *HIV among gay, bisexual, and other men who have sex with men – fact sheet*. Retrieved from: <http://www.cdc.gov/hiv/risk/gender/msm/facts/index.html>

2 DESIGNATE OLDER ADULTS WITH HIV AS A POPULATION OF “GREATEST SOCIAL NEED” IN THE REAUTHORIZATION OF THE OLDER AMERICANS ACT.

The Older Americans Act (OAA) is the country’s largest vehicle for funding and delivering services to older people in this country; recent estimates show that OAA provided \$1.9 billion to aging services nationwide.⁵ Yet despite its profound importance to millions of older people, few OAA resources are designated specifically to address older adults with HIV, LGBT older people, or older communities of color. Older adults with HIV face a variety of challenges that place them in “great social need,” including stigma and discrimination related to HIV and aging (as two factors); heightened health challenges related to the virus and to HIV medications; and a general lack of age-appropriate, HIV-related supports from practitioners across various fields. LGBT older people and older people of color face the added challenges associated with multiple forms of discrimination.

"In the next few years, half of all people living with HIV in this country will be over 50 years old. The reported incidence of HIV/AIDS among Asian Americans and Pacific Islanders (AAPIs) in general is relatively low, but because the data is not disaggregated, we do not know the impact of HIV/AIDS on Southeast Asian Americans (SEAA), much less SEAA elders. We do know that SEAA elders are often linguistically isolated and experience high rates of poverty. There is also a high level of stigma associated with HIV/AIDS across AAPI communities, resulting in low rates of testing. Culturally and linguistically competent outreach is crucial to raise awareness and prevent increased rates of HIV in our communities."

QUYEN DINH, Executive Director
Southeast Asia Resource Action Center

RECOMMENDATIONS: Congress should reauthorize and fully fund the Older Americans Act (OAA)—and explicitly include older adults with HIV in the OAA’s definition of “greatest social need.” Congress should also specify LGBT older people in the OAA’s definition of “greatest social need” and prioritize culturally and linguistically competent supports for LGBT elders and older people of color.

⁵ National Health Policy Forum, *The basics: Older Americans Act of 1965: programs and funding* (Washington, DC: NHPF: 2012). Available at nhpf.org

3 PROVIDE SUFFICIENT RESOURCES FOR THE CENTERS FOR DISEASE CONTROL AND PREVENTION TO ADDRESS HIV INFECTION AMONG OLDER PEOPLE THROUGH CULTURALLY AND LINGUISTICALLY APPROPRIATE PREVENTION CAMPAIGNS AND ROUTING TESTING.

Research shows that people age 50 and older represent one in six new HIV diagnoses.⁶ Further, 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.⁷ It also means that many older people were not tested or diagnosed early—in part because health providers mistakenly assume that older people are not sexually active, and because older people might not seek HIV testing for fear of discrimination or because of a general lack of information regarding its importance. While CDC guidelines recommend routine testing for people up to age 65, many providers are unaware of these guidelines. Further, these guidelines leave out people over age 65 who could benefit from regular HIV testing. Finally, few national or regional HIV prevention campaigns explicitly target older people, especially older people of color and LGBT older people.

RECOMMENDATIONS: The Centers for Disease Control and Prevention (CDC) should be appropriately funded to 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. In addition, the CDC and the United States Preventative Services Task Force should re-examine its testing recommendations to encourage regular HIV testing among people older than 65 and to better promote these guidelines among clinicians and the broader public.

WHY THIS MATTERS TO THE DIVERSE ELDERS COALITION: Among other examples, research shows that 31 percent of African Americans adults have never been tested and more than 70 percent report not being offered an HIV test by their health care providers.⁸ Further, many LGBT older people report delay visiting a health care provider out of fear of discrimination.

⁶ CDC (2013) *HIV surveillance report, 2011; vol. 23*. Retrieved from: http://www.cdc.gov/hiv/pdf/statistics_2011_HIV_Surveillance_Report_vol_23.pdf

⁷ CDC (2013) *HIV surveillance report, 2011; vol. 23*. Retrieved from: http://www.cdc.gov/hiv/pdf/statistics_2011_HIV_Surveillance_Report_vol_23.pdf

⁸ CDC (2012) *Expanded HIV testing and African Americans – fact sheet*. Retrieved from: http://www.cdc.gov/hiv/resources/factsheets/pdf/expanded_HIV_testing_and_african_americans.pdf

4 IMPROVE DATA COLLECTION AND REPORTING FROM THE CENTERS FOR DISEASE CONTROL AND PREVENTION ON HIV AND AGING TO BETTER ADDRESS THE EPIDEMIC'S COURSE AMONG OLDER PEOPLE.

In early 2013, the Centers for Disease Control and Prevention (CDC) released a landmark HIV surveillance report that tracked HIV infection among adults age 50 and older.⁹ The CDC should be commended for tracking and reporting HIV infection data in new five-year increments between age 50 and age 85; this data will help track the epidemic's course and inform interventions for older people with HIV across the "older" age spectrum. However, this data has not been integrated into the CDC's routine surveillance reports for people younger than 50, which limits the ability to readily compare data across age, gender, race, ethnicity, sexual risk and other variables. Further, the available data on HIV testing, and AIDS-related morbidities and mortality rates among older people is limited, especially in regards to LGBT older people and older people of color.

RECOMMENDATIONS: 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 also 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.) Finally, 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.

WHY THIS MATTERS TO THE DIVERSE ELDERNS COALITION: From 2007 to 2009, the estimated number of AIDS-related deaths among older adults age 45 and older increased 27 percent. In 2009, 48 percent of those deaths were African American and 16 percent were Latino.¹⁰

"There is a limited amount of research on the numbers of older American Indian and Alaska Native (AI/AN) elders living with HIV/AIDS today. We know other factors such as the life expectancy of an AI/AN elder is shorter than for other races in the United States. It is also known that AI/AN access to health care are poor. Many Older AI/ANs see the devastation HIV/AIDS can cause and are talking out loud about the disease and are open to learning more to support their communities."

RANDELLA BLUEHOUSE
Executive Director
National Indian Council on Aging

⁹ CDC (2013) *HIV surveillance report: supplemental report vol. 18, number 3*. Retrieved from: http://www.cdc.gov/hiv/pdf/statistics_2010_HIV_Surveillance_Report_vol_18_no_3.pdf

¹⁰ CDC (2013) *HIV surveillance report: supplemental report vol. 18, number 3*. Retrieved from: http://www.cdc.gov/hiv/pdf/statistics_2010_HIV_Surveillance_Report_vol_18_no_3.pdf

5 INCREASE MEDICAID EXPANSION OFFERED THROUGH THE AFFORDABLE CARE ACT, ENSURING THAT ALL OLDER ADULTS WITH HIV OBTAIN THEIR NECESSARY HEALTH COVERAGE AND MEDICATIONS.

The Affordable Care Act (ACA) has expanded health coverage for millions of people nationwide, including older people with HIV, many of whom are people of color and LGBT. For people with HIV, the ACA offers important protections; for example, people with HIV can no longer be denied coverage or charged more because of their HIV status. People with HIV rely heavily on Medicaid: people with HIV are three times more likely to be covered by Medicaid than the general population, due in large part to high disability rates, multiple chronic conditions and the low-income realities that qualify many people with HIV for Medicaid. Unfortunately, only 27 states (including Washington, DC) have adopted the Medicaid expansion, leaving many people with HIV without better health coverage; several of these states have high new infection rates, low rates of overall insurance coverage and troublesome racial health disparities. New research from the Kaiser Foundation has found that there are 200,000 people with HIV who could gain new coverage under ACA—through Medicaid expansion and the state Marketplaces—if all states were to expand Medicaid and if all people with HIV were in care.

RECOMMENDATIONS: All states should adopt the Medicaid expansion offered through the Affordable Care Act. The Medicaid expansion and the state Marketplaces should ensure that older adults with HIV have access to robust HIV medication coverage as part of the Essential Health Benefits packages, as defined by the Center for Medicare and Medicaid Services (CMS). State government leaders and health reform advocate should partner with organizations working with older communities of color and older LGBT people to ensure that Medicaid expansion efforts engage the diversity of people aging with HIV.

WHY THIS MATTERS TO THE DIVERSE ELDERS COALITION: Among adults, people of color are more likely to be uninsured than whites (27% vs. 15%), with Latino people showing the highest rate of uninsured people (33%).¹¹ Overall, more than half (53 percent) of uninsured people of color have incomes at or below the new Medicaid expansion limit.¹²

¹¹ The Henry J. Kaiser Family Foundation. (2013) *The impact of the coverage gap in states not expanding Medicaid by race and ethnicity – issue brief*. Retrieved from: <http://kaiserfamilyfoundation.files.wordpress.com/2013/12/8527-the-impact-of-the-coverage-gap-in-states-not-expanding-medicaid.pdf>

¹² The Henry J. Kaiser Family Foundation. (2013) *The impact of the coverage gap in states not expanding Medicaid by race and ethnicity – issue brief*. Retrieved from: <http://kaiserfamilyfoundation.files.wordpress.com/2013/12/8527-the-impact-of-the-coverage-gap-in-states-not-expanding-medicaid.pdf>

6 INCREASE FUNDING FOR THE RYAN WHITE PROGRAM, ENSURING THAT MILLIONS OF OLDER PEOPLE RECEIVE THE MEDICAL CARE AND SUPPORT SERVICES THEY NEED.

The Ryan White Program continues to serve as a critical support for people with HIV, including people age 50 and older. The median age for people with HIV is 58, which means that many of them are not eligible for Medicare or for other services funded through the Older Americans Act. Many older people with HIV rely on Ryan White-funded programs for a host of services, including the AIDS Drug Assistance Program (ADAP), which assists with the cost of HIV medications, as well as transportation support and case management. Unfortunately, the Ryan White Program has been essentially flat-funded for the last decade despite the ongoing severity of the epidemic, especially among older people, people of color and LGBT people. Given that many states have opted to not expand Medicaid, and many of those states have been ravaged by the AIDS epidemic, Ryan White remains vitally important to the health and support needs of older people with HIV.

“SAGE’s vast experience with LGBT older people around the country has shown us the profound impact that HIV/AIDS has had on their lives. Many LGBT older people are longtime survivors and now struggle with both the challenges of aging with HIV and the unfortunate stigma that’s too often present in the aging and long-term care system. Others are newly infected, which speaks to the importance of prevention campaigns aimed at older people. And many helped pave the way for the LGBT rights we are witnessing today, including remarkable wins for HIV/AIDS that helped make HIV a more manageable, chronic condition. We must band together to ensure that all older people with HIV, including LGBT people, can live out the dreams they have envisioned.”

MICHAEL ADAMS, Executive Director
Services & Advocacy for GLBT Elders

RECOMMENDATIONS: Congress should fully fund the Ryan White Program or, at a minimum, fund the program at the level requested in the President’s Fiscal Year 2015 Budget.

WHY THIS MATTERS TO THE DIVERSE ELDERS

COALITION: More than 70 percent of Ryan White HIV/AIDS Program clients are people of color¹³ and in 2010, 39 percent of Ryan White HIV/AIDS Program clients were MSM (men who have sex with men).¹⁴ In June 2013, 66 percent of AIDS Drug Assistance Program (ADAP) were people of color¹⁵ and 54% of ADAP clients were older adults.¹⁶

¹³ U.S. Department of Health and Human Services (HHS), Health Resources and Services Administration (HRSA), HIV/AIDS Bureau (2013) *The Ryan White HIV/AIDS Program – program fact sheets*. Retrieved from: <http://hab.hrsa.gov/abouthab/files/programoverviewfacts2012.pdf>

¹⁴ HHS HRSA the HIV/AIDS Bureau (2012) *The Ryan White HIV/AIDS program – population fact sheet*. Retrieved from: <http://hab.hrsa.gov/abouthab/populations/habmsmfsaug2012.pdf>

¹⁵ National Alliance of State & Territorial AIDS Directors (NASTAD) (2014) *National ADAP monitoring project: annual report*. Retrieved from: <http://www.nastad.org/docs/NASTAD%20National%20ADAP%20Monitoring%20Project%20Annual%20Report%20-%20February%202014.pdf>

¹⁶ NASTAD (2014) *National ADAP monitoring project: annual report*. Retrieved from: <http://www.nastad.org/docs/NASTAD%20National%20ADAP%20Monitoring%20Project%20Annual%20Report%20-%20February%202014.pdf>

7 INCREASE SUPPORT FOR NATIONAL INSTITUTES OF HEALTH RESEARCH ON HIV AND AGING AMONG DIVERSE POPULATIONS TO BETTER UNDERSTAND THE EPIDEMIC AMONG OLDER ADULTS WITH HIV.

Older adults with HIV remain profoundly understudied as a population in bio-medical, clinical and social science disciplines. The general lack of research hinders the treatment and care of this population, especially among groups that have been disproportionately impacted by HIV such as LGBT people and people of color. An April 2011 gathering of HIV scientific experts—the NIH Office of AIDS Research Special Working Group on HIV and Aging—affirmed these concerns and noted various priority research areas, including multi-morbidity management, behavioral health needs and caregiver support resources. The need to study and understand the realities of older adults with HIV grows as rapidly as the population.

RECOMMENDATIONS: The National Institutes of Health (NIH) should be appropriately funded to 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). Additionally, NIH should support research in the priority areas identified by the NIH Office of AIDS Research Special Working Group on HIV and Aging, including but not limited to multi-morbidity management, behavioral health needs and caregiver support resources.

WHY THIS MATTERS TO THE DIVERSE ELDERS COALITION: On average, older adults ages 60 and older have more than two chronic diseases.¹⁷ An ACRIA study of 1,000 HIV positive adults age XX and older found that 91 percent had one comorbidity and 77 percent had two or more comorbidities. The most common comorbidities in that study were depression (52%), arthritis (31%), hepatitis (31%), neuropathy (30%), and hypertension (27%).¹⁸

¹⁷ Schoenberg, E., Kim, H., Edwards, W., & Fleming ST. (2007) *Burden of common multiple-morbidity constellations on out-of-pocket medical expenditures among older adults*. Retrieved from: <http://www.ncbi.nlm.nih.gov/pubmed/17766664>

¹⁸ Karpiak, S.E., Shippy, R.A. & Cantor, M.H. (2006) *Research on older adults with HIV*. New York: AIDS Community Research Initiative of America.

8 DEVELOP U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES TREATMENT GUIDELINES FOR THE CLINICAL CARE OF OLDER PEOPLE WITH HIV—AND SUPPORT DEMONSTRATION PROJECTS AND TRAINING THAT IMPROVE HIV CARE.

A 2012 report from the AIDS Community Research Initiative of America (ACRIA), the American Academy of HIV Medicine and the American Geriatrics Society called brought attention to the importance of developing clinical guidance for HIV practitioners for a growing population of older adults with HIV.¹⁹ According to the report, effective HIV treatment has extended the lives of people with HIV, yet the combination of the virus and HIV treatment (as two primary factors) has also led to increased comorbidities among people with HIV as they age, including cardiovascular disease, kidney impairment, neurocognitive decline and more, which requires “the attention and expertise of multiple health care domains and their providers.” This trend also calls for widely adopted clinical guidance for people treating and working with people with HIV in areas such as detection and screening for HIV, sexual health, depression, substance use disorders and many other areas outlined in the 2012 report. Finally, proper training and tested interventions are crucial to ensuring that practitioners are effectively working with the full diversity of older adults with HIV, including older people of color and LGBT elders.

RECOMMENDATIONS: The U.S. Department of Health and Human Services 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. The 2012 report referenced above provides an important starting point for these guidelines. Additionally, the Health and Human Services Administration should support targeted demonstration projects and training initiatives for older adults with HIV, with an emphasis on the unique needs of older people of color and LGBT elders.

WHY THIS MATTERS TO THE DIVERSE ELDERS COALITION: A recent HIV care and treatment study published in *JAMA Internal Medicine* showed that Hispanic/Latinos diagnosed with HIV are less likely than whites to be linked to care, retained in care, receive antiretroviral treatment and achieve adequate viral suppression.²⁰

¹⁹ The HIV and Aging Consensus Project (2012) *Recommended treatment strategies for clinicians Managing older patients with HIV*. Retrieved from:

http://www.aahivm.org/Upload_Module/upload/HIV%20and%20Aging/Aging%20report%20working%20document%20FINAL%2012.1.pdf

²⁰ CDC (2014) *Health Disparities in HIV/AIDS, Viral Hepatitis, STDs, and TB*. Retrieved from: <http://www.cdc.gov/nchstp/healthdisparities/Hispanics.html>

“As in many other populations, HIV/AIDS in the AAPI community can be a highly stigmatized topic, resulting in underreporting and a lack of accessible information and education. In addition to the cultural stigma, language barriers and lack of access to health care, may also contribute to the underreporting. While the total number of reported AIDS cases has generally declined over the past five years for the White population, the total number of reported AIDS cases has increased for Asian Americans. Additionally, Asian American women are 20 percent more likely to be diagnosed with HIV than White women. The lack of discussion and accessible information around HIV/AIDS may cause the AAPI population to get HIV testing and medical help at a later stage in the disease and a later stage in life. HIV/AIDS affects AAPIs of all ages and as such, increased education, awareness, and prevention is critical for the health of our population.”

CHRISTINE TAKADA, President and CEO
National Asian Pacific Center on Aging

"Hispanics represent 17% of the U.S. population yet comprise more than 21% of all new HIV infections. At three times the rate of HIV infection as their White counterparts, HIV presents a serious public health threat to the Latino community. Moreover, 16% of all new HIV infections annually are among Hispanic older adults. Poverty, limited access to health services, and social isolation among elderly Latinos are roadblocks to effective HIV treatment. Additionally, cultural gender norms-- such as machismo and homosexuality-related stigma— can keep HIV positive Latino seniors from obtaining the necessary social support vital to effectively managing their illness. Diverse elders should never face a serious medical condition such as HIV/AIDS in seclusion, without resources, or in shame, but the sad reality is that many do. These are just a few of the reasons NHCOA includes HIV/AIDS work in its health portfolio. By coming together from various areas of specialization for a common goal, we can increase awareness, decrease stigma, and more effectively address HIV/AIDS among Hispanic older adults and other diverse elders."

DR. YANIRA CRUZ, President and CEO
National Hispanic Council on Aging

ABOUT THE DIVERSE ELDERS COALITION:

The Diverse Elders Coalition (DEC) advocates for policies and programs that improve aging in our communities as racially and ethnically diverse people; American Indians and Alaska Natives; and lesbian, gay, bisexual and/or transgender people.

Together, we are made up of five national organizations representing a growing majority of millions of older people throughout the country—racially and ethnically diverse older adults; LGBT older adults; and poor and low-income older adults. We have come together to promote policy changes and programmatic solutions that respond to this demographic shift and will remove the barriers facing our communities. We envision a world where all older adults can live full and active lives as they age.



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