Overview

As we engage a pro-equality administration in the White House, on the heels of an extraordinary four years, when there was a vacuum in leadership in Washington, and an outright hostility towards many of the communities impacted by HIV, this document lays a foundation for policy change to address the aging of the epidemic. This report names a half-dozen practicable and impactful federal policy goals related to HIV and aging. For each policy priority, we state our goal, why we need to take action, how it will help older adults living with or at risk for HIV, who should take action, and how we plan to accomplish the goal. The report discusses updating prevention and national treatment guidelines to improve testing rates for older adults, dedicating resources to developing and evaluating prevention campaigns and interventions that target older adults, and creating new national treatment guidelines focused on managing the physical and mental/behavioral health care of older people living with HIV. This is necessary, in part, because too many older adults and their providers don’t understand that older people are at risk for HIV. The report also advocates for improving HIV care and bolstering engagement, to improve services and supports for older adults with HIV/AIDS, because better care not only helps those who are positive stay healthy - it also reduces the risk of infecting others. We discuss the importance of expanding workforce and training to increase cross-training and coordination for medical and other service providers in order to build HIV/aging cultural competencies and bolster the HIV/aging provider workforce. This is needed because HIV providers, infectious disease doctors, and primary care physicians are too often not well-versed/trained in geriatric care principles and on the needs of older patients. The advocates for HIV/aging research at NIH and elsewhere to facilitate research that addresses psychosocial issues affecting people aging with HIV, because short of a cure, addressing psychosocial issues affecting everyday functioning and quality of life for people aging with HIV is imperative to insuring healthy aging with HIV. We recognize that we must remain vigilant to protect safety net programs, including keeping the Affordable Care Act (ACA) in place, expanding rather than block-granting Medicaid, and fully funding the Ryan White HIV/AIDS Program, because, in short, not everyone who currently needs to be covered is covered. Lastly, the report talks about the importance of influencing and working with policy makers by strategically positioning older adults with HIV and those working with them at the tables where decisions are made. We believe it’s important for older adults with HIV and those working with them have a direct say in our federal HIV research and policy agenda.
Six Policy Goals

1. Update Prevention and National Treatment Guidelines

The CDC Should Remove Upper Recommended Age Limit for HIV Testing
Current US Centers for Disease Control and Prevention (CDC) Guidelines state:

Screening for HIV Infection - In all health-care settings, screening for HIV infection should be performed routinely for all patients aged 13–64 years. Health-care providers should initiate screening unless prevalence of undiagnosed HIV infection in their patients has been documented to be <0.1%. In the absence of existing data for HIV prevalence, health-care providers should initiate voluntary HIV screening until they establish that the diagnostic yield is <1 per 1,000 patients screened, at which point such screening is no longer warranted.¹

Our goal is to have the upper age limit removed, i.e., “In all health care settings, screening for HIV infection should be performed routinely for all patients aged 13 year and older.”

Why is this needed? Many older adults (and their providers) don’t think that older people are at risk for HIV, yet 21% of new infections occur over the age of 50. In 2015, nearly 1,000 adults 65 and older in the U.S. were diagnosed with HIV (n=888).² Of adults 65 and older diagnosed with HIV in 2015, 80% received a concurrent AIDS diagnosis (Stage 3), associated with poor clinical outcomes and increased morbidity and mortality, and indicative of HIV testing in later stages of infection. Failure to engage adults of all ages in HIV testing undercuts test-and-treat strategies of prevention and ending the AIDS epidemic. While the CDC has balked at the cost-benefit of extending HIV testing beyond age 64, research disputes this conclusion.³ In November 2016, New York State passed Public Health Law 2781-a, which removed the upper age limit for recommended HIV testing.²

Who must take the action? It is up to the CDC and the US Preventative Services Task Force to change their recommendations/guidelines.

How do we accomplish this? Pressure from Congress and advocacy organizations.

What additional measures can be taken to advance testing among older adults? The CDC and its sister agencies should dedicate resources to developing and evaluating prevention campaigns and interventions that target older people age 50 and older. To ensure that these campaigns reach older people of color; gay and bisexual men, other men who have sex with men (MSM), and transgender older people, these campaigns should place a specific emphasis on working with organizations that engage these populations to ensure culturally and linguistically appropriate messaging, representations, and implementation. These campaigns should also encourage the use of PrEP among older women and men. The Health Resources and
Services Administration’s (HRSA’s) HIV/AIDS Bureau (HAB) should encourage Ryan White recipients to use testing resources to specifically target older adults by ensuring that planning councils include such testing as a priority, and that contracts are secured with the organizations most able to reach these individuals. The CDC and its partner agencies should increase collaboration across HIV services/testing networks, the aging network, and faith-based community organizations, to improve testing rates among older adults. The CDC, with the support of the LGBTQ+ philanthropic community, should develop and disseminate HIV testing/prevention/PrEP/PEP social messaging and marketing campaigns targeted at the most at-risk older adults.

**How can we do this?** In addition to advocating for the CDC and the other HHS component agencies to take the actions outlined above, we can advocate for the LGBTQ+ philanthropic community to increase HIV-related grants, to better address the needs of at-risk older adults. And we can advocate for the White House Office of Faith-based and Neighborhood Partnerships to engage in efforts to reduce homophobia and HIV fears/myths and to increase HIV testing among older adults, through specific efforts with faith-based organizations.

**National Treatment Guidelines**

While the most effective prevention occurs prior to infection, treatment of HIV not only lessens its effects, but also lessens the likelihood of spreading the infection. Treatment and prevention go hand and hand, and with respect to older adults, both fall woefully short. A new set of national treatment guidelines focused on managing the physical and mental/behavioral health care of older people living with HIV should require that physicians with geriatric and infectious disease specialties coordinate treatment for persons over 50; provide resources for coordination of community support programs that promote social networks tied to risk reduction and treatment adherence, specifically among older people living with HIV; and establish models that incorporate long term survivor skills-building among newly diagnosed persons of all ages.

**Who must take the action?** It is up to the NIH’s Office of AIDS Research, Advisory Council, to issue the national treatment guidelines.

**How do we accomplish this?** Pressure from policy makers and advocacy organizations.

### 2. Improve HIV Care and Engagement

Our goal is to improve care, services, and supports for older adults with HIV/AIDS. Why is this needed? Better care not only helps those who are positive stay healthy; it also reduces the risk of infecting others.

**Who must take action and how?** There a number of actions HHS and its component agencies can take. HHS should issue standards of care for clinicians caring of older people with
HIV. Such standards cannot be developed without clinical observations of large cohorts of this population, which have yet to be achieved. The Health Resources and Services Administration’s (HRSA’s) HIV/AIDS Bureau (HAB) should consider a Special Projects of National Significance (SPNS) demonstration project to address the specific needs of an aging epidemic, particularly in light of the well-documented multi-morbidity and burden of disease, and the need for trauma-informed care. The CDC’s Clinical Care Guidelines should recognize the need to evolve from aging with HIV to healthy aging with HIV, beyond viral suppression, and into preventing and managing co-morbidities.

A number of component agencies of HHS should coordinate and partner with HHS’s Administration for Community Living (ACL), to encourage, engage, and educate the aging network on the challenges associated with HIV and aging. HHS’s Office of HIV/AIDS and Infectious Disease Prevention (OHAIDP) should convene a meeting with the Substance Abuse and Mental Health Services Administration (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, including a focus on depression.

The Domestic Policy Council (DPC), Office of National AIDS Policy (ONAP), and ACL should consider how to secure targeting of services and supports and data collection on older adults with HIV under the Older Americans Act. Likewise, within the bounds of statutory authority, they should address age restrictions on senior programs that limit health care, services, and/or supports to those over a certain age.

**How do we accomplish this?** Advocate for HHS more generally, and HRSA, SAMHSA, DPC, ONAP, and ACL more specifically to take the steps outlined above.

### 3. Expand Workforce and Training

Our goal is to increase cross-training and coordination for medical and other service providers to build HIV/aging cultural competencies and to bolster the HIV/aging provider workforce.

**Why is this needed?** HIV providers, infectious disease doctors, and primary care physicians are too often not well-versed/trained in geriatric care principles and on the needs of older patients. Older adults with HIV can help play a role.

**Who must take action?** HRSA should require HIV and aging-specific training/technical assistance (TA)/capacity building assistance (CBA) from all grantees in response to a rapidly aging epidemic. It should also require training of all providers, not just those in receipt of Ryan White money. HRSA 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, it can 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. Further, we could require all physicians who provide care to persons 50-years and older to receive professional CME training on HIV prior to annual recertification/license renewals. A requirement of this type is already in place in the District of Columbia.\textsuperscript{vi}

Older adults with HIV face a challenging employment environment and can struggle to overcome the economic disparities that can be particularly pronounced among racial and ethnic minorities as well as women. Providing older PLWH with onramps to employment, and providing proper training and education to those who provide care and assistance to older PLWHA, can be complimentary goals. The clinical providers of health services need more training on HIV and aging. HIV and older adult service organizations can make efforts to provide those onramps to job training and employment by developing career ladders for persons to work as community health workers, Peer Navigators or Patient Assisters. These individuals can in turn assist with training home health aides, certified nursing assistants, and staffs of nursing homes and assisted living facilities, state and local offices on aging, and others who provide direct services to people over the age of 50 who are living with HIV, on basic HIV, cultural competency, sexuality, and aging.

\textbf{How can this be accomplished?} Advocate for HHS and HRSA to take the steps outlined above.

\section*{4 - Promote HIV/Aging Research at NIH and Elsewhere}

Here we focus attention on psychosocial issues and use of HIV/aging research as a paradigm to address aging issues in general.

Our goal is to facilitate research supported by NIH and other funders that addresses psychosocial issues affecting people aging with HIV, including mental/behavioral health, social supports and caregiving, service utilization, sexual health, resilience and positive psychological functioning, and the impact of HIV stigma.

\textbf{Why is this needed?} Short of a cure for HIV, treatment, and addressing care and other psychosocial issues affecting everyday functioning and quality of life for people aging with HIV are imperative to insure healthy aging with HIV. There is a burgeoning scientific literature that provides the evidence base that psychological and social factors are both affected by and contribute to physiological functioning and clinical outcomes. Hence, the prominence of the bio-psycho-social model, which is prevalent in the geriatrics/gerontological literature.

In 2011, the NIH Office of AIDS Research (OAR) convened a special working group on HIV and aging that it charged with identifying research priorities to address growing older with HIV. The
report for this working group identified four domains of research and priority research areas within each domain, which JAIDS published in a special supplement.\textsuperscript{vii}

One of these four domains considered the psychosocial issues outlined above (the other three were clinical/biomedical). The report of the working group resulted in two subsequent program announcements from NIH to address HIV and aging.\textsuperscript{viii} It is not clear nor easy to determine how many research programs NIH has funded under these PARs that address psychosocial issues. Literature searches of popular databases (PubMed, Google Scholar), however, would suggest that most current work in this field concerns biomedical and clinical vs. psychosocial domains.

The failure to address issues facing long-term HIV survivors is a glaring gap in federal HIV/aging policy. At present, there is no consensus on how to define long-term survivors. Some studies, for example, have used pre-HAART/post-HAART eras as a demarcation, while others consider the length of time since HIV diagnosis. While most long-term survivors are older adults (50+), some who were perinatally infected are adolescents or young adults. The long-term psychological and social impacts of living with HIV are poorly understood.

Lastly, understanding the psychosocial issues around HIV and aging may result in a broader societal impact. Dr. Linda Fried, Dean of the Mailman School of Public Health at Columbia University, stated in 2009 that understanding HIV and aging could serve as a paradigm for a better grasp of aging issues that affect the general population.\textsuperscript{ix} Others have echoed this idea since that time.

**What is needed?** NIH must reactivate/reconvene the NIH OAR Working Group on HIV and Aging that has been dormant since 2012, to review studies funded under the original PARs and reassess funding priorities for HIV and aging. A special working group on psychosocial issues may be warranted. Increased targeted funding for psychosocial issues among those aging with HIV by NIH and other government agencies, non-profits, foundations, and other funders (e.g., CDC, amfAR). Create a clearinghouse on HIV and aging psychosocial research to better catalogue efforts in this area and identify research and knowledge gaps. Continue funding for the Patient-Centered Outcomes Research Institute (PCORI). These funds allow impacted community members to be included in the process of identifying issues literature does not always explain and of which researchers are not always aware. Incorporate requirements that research include: aging women and men; and provide funding to study the specific effects of long-term used of ARTs on long term survivors (LTSs) (men/women/African Americans). Although people are living longer because of biomedical interventions, there is little data on the effects of taking medications over time. If this were known, perhaps strategies can be developed that will assist people with better adherence, fewer polypharmacy issues, and alternate and/or supplemental treatment options for LTSs.

**How to accomplish this?** Develop a broad coalition of HIV stakeholders who recognize the importance of this work and who can direct advocacy efforts at Congress and the White House.
5. Play Defense

The Affordable Care Act, Medicaid, and HIV Care

Our goal is to keep the Affordable Care Act (ACA) in place, expand rather than block-grant Medicaid, and fully fund the Ryan White HIV/AIDS Program, all while these programs have faced unprecedented cuts because of the Trump administration’s tax cuts.x

Why are these programs needed? The ACA requires insurance providers to provide insurance for all who apply and to offer comparable rates to all, without regard to preexisting conditions such as HIV infection.xi

Until the ACA, adults without dependent children living with them or who were not pregnant did not qualify for Medicaid unless they were disabled. For HIV-infected individuals, this meant having an AIDS diagnosis. Under the ACA, however, states have the option to expand Medicaid eligibility to all adults up to 138% of the federal poverty level (FPL), as determined each year by the Department of Health and Human Services.xii Medicaid expansion under the ACA has resulted in a large increase in insurance coverage for people living with HIV. The percentage of people with HIV in care, on Medicaid, rose from 36% in 2012 to 42% in 2014; the percentage of people with HIV in care, on Medicaid, living at less than 100% of the FPL, rose from 53% in 2012 to 60% in 2014; and the percentage of people with HIV in care, living at less than 100% of the FPL, who were uninsured, dropped from 22% to 15% between 2012 and 2014.xiii

Other key elements of the ACA include state health insurance marketplaces, through which affordable and often subsidized insurance is offered; the individual mandate to have insurance; a guarantee of access to “essential health benefits,” including preventive services, prescription drugs, and mental health and substance use treatment; and no annual or lifetime limits on how much coverage can be provided.xiv These changes are especially important for those disproportionately denied or lacking insurance coverage and access to health care, including Black and Hispanic Americans, people living with HIV, xv and LGBTQ+ people.xvi The ending of annual and lifetime spending caps and discrimination based on preexisting conditions is important for people with many complex, chronic diseases, including people living with HIV.

In 2010, 28% of people in the United States living with HIV were virally suppressed, compared to 49% in 2014.xvii Cohen et al. have found that earlier treatment decreases HIV transmission, so programs that enhance retention in care may save costs by decreasing new HIV infections.xviii
Why the Ryan White Program is Still Needed

In 2013, about 30% of people living with HIV (some 360,000 individuals) lacked insurance coverage and were not eligible for Medicaid. Many became eligible for Medicaid in 2014. As of July 2018, 34 states— including Washington, DC— have expanded Medicaid eligibility.xix Many states that have rejected the Medicaid expansion are home to some of the most striking health disparities, particularly for racial/ethnic minorities, low-income people, and immigrants. The private insurance premium subsidy covers only people with incomes 400% or less of the FPL. In the 17 states that had not expanded Medicaid as of June 2018, some of the poorest people in those states—more than four million individuals—remain uninsured.xx

Even were key provisions of the ACA to continue, people living with HIV would continue to need the critical services funded by the Ryan White HIV/AIDS Program well into this decade and beyond. This is especially true in the Medicaid non-expansion states. In many Southern states, one must be extremely poor and have dependent children to qualify for Medicaid. For example, in Alabama and Texas, a family of three must earn 18% of the FPL or less—$3,740 per year—to qualify for Medicaid.xxx

Childless, non-pregnant, non-disabled adults in non-Medicaid expansion states cannot qualify, no matter how low their incomes. Many thousands of poor people with HIV are ineligible for Medicaid but do not earn enough (≥ 100% of the FPL) to qualify for subsidies to support their purchase of insurance in the marketplaces. This population falls into what is known as the “coverage gap.” The coverage gap is created by states’ non-expansion of Medicaid eligibility.xxxi Ryan White-funded services are especially important for this population of people living with HIV who cannot access insurance.

Contributing to the increasing complexity of HIV care is the aging of the population of PLWHA. As of 2014, 45% of people living with HIV in the United States were 50 and over.xxxii As people grow older with HIV and live decades with the virus, they are likely to develop comorbidities.xxxiii Common comorbid conditions among older adults living with HIV include liver, kidney, and cardiovascular disease; cognitive impairment; depression; and neuropathy.xxxiv Coinfections such as hepatitis C—found among one third of HIV-infected Americans.xxxv—are among the causes of comorbidities such as cirrhosis and hepatitis C virus–related mortality.xxxvi.xxxvii

Repeal of the Affordable Care Act and Cuts to Medicaid will Disproportionately Hurt People Living with HIV

The Trump–Pence Administration and Congress repeatedly tried to repeal the Affordable Care Act and reduce the number of people who enroll. Block granting Medicaid to the states would likely dramatically decrease Medicaid spending, end its guarantee as an entitlement, shift costs to states that cannot deficit spend due to balanced budget amendments, and leave millions uninsured. Many of the 20 million newly insured under the ACA are insured by Medicaid, including
thousands of people living with HIV. Many people living with HIV who were recently able to access private insurance or Medicaid would likely lose that coverage and become newly dependent on the Ryan White HIV/AIDS Program for their care as a payer of last resort. This is why HIV and other public health advocates oppose the repeal of the ACA, including the Medicaid expansion.

**How to accomplish this?** Develop a broad coalition of HIV stakeholders who recognize the importance of this work, who can continue to direct advocacy efforts at Congress and the White House (should that one day be needed again).

6. **Influence and Work with Policy Makers**

**What is our goal?** Strategically position older adults with HIV and those working with them at the tables where decisions are made. These decisions include whether to engage in research on the impact of the disease on long-term survivors, whether and how to establish targeted prevention and treatment strategies and guidelines, and other questions critical to this community. More specifically, we aim to nominate or seek appointment of older adults with HIV and those who work with them on key committees and working groups within NIH and its component agencies.

**Why is this important?** It is important for older adults with HIV and those working with them have a direct say in our federal HIV research and policy agenda.

**How to accomplish this?** Advocate for the NIH Office of AIDS Research to include older adults with HIV and those who work with them on or in the Office of AIDS Research Advisory Council (and its working groups), the HIV Treatment Guidelines Working Group, the Genomics/Genetics Research Working Group, and the AIDS and Aging Working Group. Advocate for HRSA to include older adults with HIV and those who work with them on the CDC/HRSA Advisory Committee on HIV, Viral Hepatitis and STD Prevention and Treatment (CHACHSPT). And explore other working groups and advisory committees in federal HIV policy making circles where the voices of older adults with and at risk for HIV can and should be heard.

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