

December 14, 2020

U.S. Department of Health and Human Services
Office of Infectious Disease and HIV/AIDS Policy
Office of the Assistant Secretary for Health

Re: HIV National Strategic Plan for the United States: A Roadmap to End the Epidemic 2021–2025

Submitted via HIVPlanComments@hhs.gov

Dear colleagues,

We are a coalition of organizations representing health care and service providers, researchers, advocates, and people living with HIV who write to comment on the draft HIV National Strategic Plan released on World AIDS Day, 2020. The draft plan represents the efforts of many public health professionals across a broad range of federal agencies. We thank you for your hard work developing this draft plan over the past couple of years, and for considering our comments as you develop the final plan.

We believe that a critical gap in the draft plan is the dearth of attention paid to older adults living with HIV (PLWH) and long-term survivors (LTS). **We encourage you to significantly increase the focus on older PLWH and LTS in the plan.** Half of PLWH in the U.S. are age 50 or older. Older PLWH experience multiple comorbidities^{1,2} and “increased prevalence of geriatric syndromes,”³ such as falls, frailty, and polypharmacy.⁴ Older PLWH and LTS are entering elder service and care systems often woefully unprepared to care for them.⁵ For these reasons, attention to older PLWH and LTS should be a central focus of the HIV National Strategic Plan for the United States.

The draft plan describes the importance of “[s]upport[ing] all people with HIV to achieve and maintain viral suppression and improve health-related quality of life as they age with HIV” (page 8). It also calls for the integration of HIV prevention and care into treatment of “substance use disorders, and other public health efforts” (p. 10). We strongly agree, and call on the HIV National Strategic Plan for the United States to incorporate two changes to better achieve these goals:

First, explicitly call for the integration of federal HIV care and prevention efforts with federal elder services and care. Research indicates that many older Americans are more likely than younger age cohorts to hold inaccurate views about how HIV is transmitted—for example, believing that it can be

¹ Applebaum, A., & Brennan, M. (2009). Mental health and depression. *Research on older adults with HIV: an in-depth examination of an emerging population*. New York: Nova Science, 27-34.

² Karpiak, S. E., & Brennan, M. (2009). The Emerging Population of Older adults with HIV and Introduction to ROAH the Research Study In M. Brennan, S. E. Karpiak, R. A. Shippy, & M. H. Cantor (Eds.), *Older Adults with HIV: An In-Depth Examination of an Emerging Population* (pp. 13-26). New York: Nova Science Publishers.

³ Sangarlangkarn, A., & Appelbaum, J. S. (2020). Comprehensive Geriatric Assessment in Older Persons With HIV. *Open forum infectious diseases*, 7(11), ofaa485. <https://doi.org/10.1093/ofid/ofaa485>

⁴ Guaraldi G, Milic J, Mussini C (2019). Aging with HIV. *Curr HIV/AIDS Rep*. 16:475–81.

⁵ Cahill S & Valadez R. Growing Older with HIV/AIDS: New Public Health Challenges. *Am J Public Health*. 2013;103(3):e7-e15.

transmitted via sharing a drinking glass, swimming pool, or toilet seat.⁶ Older Americans are also more likely than younger age cohorts to morally disapprove of homosexuality.⁷ These are the age peers in elder service and care settings that older PLWH—some two thirds of them LGBTQ—are encountering.

The Administration for Community Living and the Administration on Aging must coordinate closely with the Ryan White HIV/AIDS Program, the HHS Office of Civil Rights, and other HHS agencies to ensure that older PLWH and LTS can access elder services and care systems. All aging service providers, including home care aides, must be trained so that they are competent to provide affirming care to older PLWH and older LGBTQ people. The Ryan White HIV/AIDS Program and the AOA should require ongoing collaboration among local Area Agencies on Aging (AAAs), Ryan White Planning Councils, and state-integrated HIV care and prevention planning bodies.

Older PLWH and LTS often struggle to access geriatric care, which many need in their 50s due to earlier onset of many conditions associated with aging. The Ryan White HIV/AIDS Program should ensure that PLWH can access geriatric care in all Ryan White clinics. Specialists, such as cardiologists, must be trained in how to provide affirming care to LTS with lipodystrophy and other conditions.

Second, older PLWH and LTS struggle to access competent mental health care, because many therapists do not accept public or even private insurance, and due to a shortage of mental health care providers who understand the unique histories of surviving the first twenty years of the AIDS pandemic, leading to a lack of culturally competent mental health care. Many older PLWH and LTS experience similar barriers to accessing competent, affirming substance use treatment. The HHS Office of Infectious Disease and HIV/AIDS Policy and the Ryan White HIV/AIDS Program should work with SAMHSA and CMS to address these reimbursement barriers and workforce training issues.

The HIV Plan highlights that uninsurance among PLWH is down to 11%, on par with that of the general population (p. 12). This is due to the Affordable Care Act and Medicaid expansion. The HIV National Strategic Plan for the United States should encourage continued support for the ACA and further Medicaid expansion in order to continue to reduce the percentage of PLWH without insurance. This is especially important for Black, Latinx, and Indigenous people, who are less likely to be insured than White non-Hispanic and Asian American individuals.⁸ We are pleased that the plan prioritizes Black, Latino, and American Indian/Alaska Native men who have sex with men, Black cisgender women, and transgender women (p. 8). If we really want to support these groups, we must work to eliminate disparities in health insurance access, which each group continues to experience. The best way to do this is to support the ACA and Medicaid expansion in the Southern states.

The draft HIV Plan calls for us to:

⁶ Kaiser Family Foundation (2010). *2009 survey of Americans on HIV/AIDS*. <http://www.kff.org/kaiserpolls/7890.cfm>.

⁷ Anderson R., and Fetner, T. (2008). Cohort differences in tolerance of homosexuality: Attitudinal change in Canada and the United States. *Pub Op Q*. 47(2):311-330.

⁸ Artiga S (2020, October 1). Loss of the Affordable Care Act would widen racial disparities in health coverage. Kaiser Family Foundation. <https://www.kff.org/policy-watch/loss-of-the-affordable-care-act-would-widen-racial-disparities-in-health-coverage/>

Address stigma, discrimination, and other social and structural determinants of health that inhibit HIV prevention, testing, and care.

Every person with and at risk for HIV should receive diagnostic, preventive, care, treatment, and supportive services that are non-stigmatizing, or non-discriminatory, competent, and responsive to their needs (p. 22).

We agree wholeheartedly. Discrimination is a major barrier to accessing health care for LGBTQ people, and also correlates with poorer mental and physical health outcomes.^{9,10} LGBTQ people face widespread discrimination in health care, such as being verbally or physically harassed or being denied treatment altogether.¹¹ This discrimination acts as a barrier to seeking necessary routine, preventive care as well as emergency care. For example, the 2015 U.S. Transgender Survey of nearly 28,000 transgender people found that in the last year, 33% of respondents had experienced anti-transgender discrimination in health care, and 23% of respondents chose to forego necessary health care due to fear of discrimination.¹² A 2018 survey by the Center for American Progress found that 14% of LGBT respondents who had previously experienced discrimination in health care avoided seeking necessary medical care, and 17% avoided seeking preventive care in the past year.¹³ This is why the Joint Commission has required SOGI nondiscrimination policies as a prerequisite to accreditation for health care programs since 2011.

Discrimination has no place in our society, and especially in health care and social services. Unfortunately, the Trump-Pence Administration has implemented a number of regulations enabling and promoting anti-LGBTQ discrimination in health care, health insurance, and elder services (Health and Human Services Final Rule: Nondiscrimination in Health and Health Education Programs or Activities (RIN 0945-AA11)), and in more than half a trillion dollars a year in HHS-funded social services (Office of the Assistant Secretary for Financial Resources; Health and Human Services Grants Regulation (RIN 0991-AC16)). The administration has also promoted religious refusal policies that allow for anti-LGBTQ discrimination in health care and service provision.¹⁴ These discriminatory policies undermine HIV prevention and care, and any national strategies to reduce HIV transmission.

We appreciate that the draft HIV National Strategic Plan for the United States: A Roadmap to End the Epidemic 2021–2025 articulates a vision opposed to discrimination and stigma based on sexual orientation and gender identity (SOGI) along with race, ethnicity, sex, age and other factors. However, in the face of the Trump-Pence Administration’s relentless attacks on LGBTQ equality, the Strategic

⁹ Mirza S and Rooney C. (2018). *Discrimination Prevents LGBTQ People from Accessing Health Care*. Center for American Progress.

¹⁰ Reisner SL, White Hughto JM, Dunham E, Heflin K, Begenyi JB, Coffey-Esquivel J, Cahill S (2015). Legal protections in public accommodations settings: A critical public health issue for transgender and gender nonconforming people. *Milbank Quarterly*. 93(3):484-515.

¹¹ Lambda Legal. (2010.) *When Health Care Isn’t Caring: Lambda Legal’s Survey of Discrimination against LGBT People and People with HIV*. New York: Lambda Legal.

¹² James SE, Herman JL, Rankin S, Keisling M, Mottet L, Anafi M. (2016). *The Report of the 2015 U.S. Transgender Survey*. Washington, DC: National Center for Transgender Equality.

¹³ Mirza S and Rooney C. (2018).

¹⁴ Abutaleb Y (2019, November 6). Trump’s ‘conscience rule’ for health providers blocked by federal judge. *Washington Post*. https://www.washingtonpost.com/health/trumps-conscience-rule-for-health-providers-voided-by-federal-judge/2019/11/06/39aa9b74-00b1-11ea-9518-1e76abc088b6_story.html

Plan should state its support for SOGI nondiscrimination regulations in health care, health insurance, and social services, including elder services. The Trump Administration’s repeal of a SOGI nondiscrimination regulation governing the Program of All-Inclusive Care for the Elderly (PACE)—elder services and health care for frail, nursing home-eligible seniors¹⁵—hurts older PLWH and LTS. The Strategic Plan should express its opposition to such discriminatory, harmful policies, and encourage the restoration of these SOGI nondiscrimination regulations. Legal protections for sexual and gender minorities in health care are essential to the success of the HIV National Strategic Plan.

When considering the impact of stigma and discrimination, the Strategic Plan should also address how ageism, namely disparate attitudes and treatment due to a person’s age, play a role in community responses to HIV prevention, treatment, care, and support.¹⁶ There remains a widespread misconception that HIV is a disease that primarily affects the young despite epidemiological evidence to the contrary. Many older PLWH face intersecting stigmas of age, HIV serostatus, and other marginalized identities based on race or sexual orientation.^{17,18} These ageist attitudes may result in delayed HIV testing and treatment for older adults, resulting in excess morbidity and mortality. Ageism also fosters an HIV service environment that seems unwelcoming due to a lack of specialized services for older PLWH.¹⁹ Thus, addressing the harmful effects of ageism for older PLWH should be addressed in the Strategic Plan.

Finally, we wish to register concern re: the timing of this draft release and comment period. The less than two-week turnaround, just before the holidays, is unnecessarily short. We question why you do not have a more traditional public comment period of at least 30-60 days, which would allow for a broader range of review and feedback from community-based organizations.

Thank you for considering our comments. We would welcome an opportunity to help ODP to incorporate older PLWH and LTS into the HIV National Strategic Plan for the United States. Please let us know how we can assist in these efforts by reaching out to Sean Cahill at the Fenway Institute (scahill@fenwayhealth.org) or Aaron Tax at SAGE (atax@sageusa.org).

Sincerely,

The Fenway Institute

SAGE

AIDS Healthcare Foundation

¹⁵ Cahill S (2020, September). “The Best of Times...the Worst of Times”: What *Bostock v. Clayton County, Georgia* and the Repeal of Federal Nondiscrimination Rules Mean for LGBT Health. *LGBT Health*. 7(7); 345-348.

¹⁶ DeMarco, R. F., Brennan-Ing, M., Sprague, C., & Brown, S. M. (2017). Ageism, aging and HIV: community responses to prevention, treatment, care and support. In HIV and aging (Vol. 42, pp. 234-239). Karger Publishers.

¹⁷ Emler, C. A. (2006). “You’re awfully old to have this disease”: Experiences of stigma and ageism in adults 50 years and older living with HIV/AIDS. *The Gerontologist*, 46(6), 781-790.

¹⁸ Porter, K. E., & Brennan-Ing, M. (2019). The intersection of transgender identities, HIV, and aging. In *Transgender and Gender Nonconforming Health and Aging* (pp. 61-77). Springer, Cham.

¹⁹ Burchett, C. O., Shen, M. J., Freeman, R., Seidel, L., Karpiak, S., Brennan-Ing, M., & Siegler, E. L. (2020). Using Focus Group Feedback to Identify Patient-Centered Initiatives for Older Persons with HIV. *Clinical Gerontologist*, 1-12.

AIDS United
American Indian Community House
Brookdale Center for Health Aging, Hunter College, The City University of New York
Callen-Lorde Community Health Center
GLMA: Health Professionals Advancing LGBTQ Equality
Health Equity Institute, San Francisco State University
Howard Brown Health
interACT: Advocates for Intersex Youth
Legacy Community Health
Let's Kick ASS – AIDS Survivor Syndrome
Lyon-Martin Health Services
NMAC
Positively Trans
The Reunion Project
SAGE New Orleans
Silver Lining Project, THRIVE SS
TPAN (Test Positive Aware Network)
Transgender Law Center
Transgender Legal Defense & Education Fund
Whitman-Walker Institute