Enhancing HIV Inclusion in Multisector Plans on Aging:

Best Practices and Recommendations for State Leaders and Advocates

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Introduction & Background:

People of all ages diagnosed with human immunodeficiency virus (HIV) can lead longer and healthier lives when they have adequate access to medical care and community-based services. Continuous advancements in medical technology, routine HIV testing, and the development of treatments are crucial in ensuring this is possible. The Centers for Disease Control and Prevention (CDC) estimates that in 2022, more than one-half (54%) of the 1.2 million people in the United States living with HIV were over the age of 50.[1][2][3] By 2030, some parts of the country are expected to see 70% of all people with HIV being over 50. The fastest-growing age group among people living with HIV is 65 and above, with an increase from 8.9% in 2017 to 13.2% in 2022. Nearly half of all clients served by the Ryan White HIV/AIDS Program (RWHAP), a system of supports and services for low-income individuals with HIV, were over 50. Yet, the HIV community continues to experience many challenges that contribute to higher rates of mortality and greater reliance on long-term services and supports, including increased vulnerability of multimorbidity, polypharmacy compounded by rising costs of prescription medications, higher rates of poverty, housing insecurity, lack of affordable transportation, lack of culturally competent care, and many more. For more information on aging with HIV, please visit HIV.gov's Aging with HIV and HealthHIV's State of Aging with HIV Annual National Survey, which provides a breakdown of the social determinants of health (SDOH) for older persons with HIV.

As more people age with HIV, aging policies like multisector plans on aging[4] should include actions to meet the needs of older people living with HIV (see Meeting the Needs of People Aging with HIV on the Path to Ending the HIV Epidemic). According to the Center for Health Care Strategies, a multisector plan on aging is an umbrella term for a state-led, multi-year planning process that convenes cross-sector stakeholders to collaboratively address the needs of older people and people with disabilities. To help states develop multisector plans on aging, the Center for Health Care Strategies has published Nine Best Practices for Developing a Multisector Plan for Aging. Multisector plans on aging enable states to coordinate various efforts, initiatives, and projects that address the SDOH across multiple state agencies and departments. SDOH significantly impact health, well-being, and quality of life, and can significantly affect a person's chances of staying healthy as they age.[5] SDOH can be categorized into five domains according to the Healthy People 2030 framework, which includes (1) economic stability, (2) social and community context, (3) access to education and quality of education, (4) access to quality healthcare, and (5) neighborhood and built environment.

The National HIV/AIDS Strategy for the United States 2022-2025 provides a roadmap to guide federal partners and others in the vision of ending the HIV epidemic by 2030. Included are goals, objectives, and strategies meant to address individuals, the broader community, and the structural factors and inequities that contribute to the transmission of HIV. In addition, it includes aspects that impact the HIV care continuum, such as stigma and social determinants of health.

Best Practices & Recommendations

As states begin developing or updating their multisector plans on aging, this tool helps agencies and advocates identify best practices. The below resources will also provide recommendations to better incorporate the needs of older people living with HIV throughout the planning process and across the five SDOH domains.

Highlight the benefits of HIV inclusion across all sectors.

Multisector plans on aging provide an excellent opportunity to highlight the healthcare and social support needs of older people living with HIV. The Health Resources and Services Administration's (HRSA) Ryan White HIV/AIDS Program spells out these needs in its HIV Aging Technical Expert Panel Executive Summary. A study in 2021 examined the cumulative social and economic disadvantages and the accumulation of SDOH indicators across the five domains among people of all ages living with HIV.[6] That study found that 83% of participants reported at least one SDOH indicator, and that having just one SDOH indicator was highly associated with missing medical appointments and lower adherence to Antiretroviral therapy (ART). Evaluation of the Aging with HIV Initiative as part of the Ryan White HIV/AIDS Program (RWHAP) Part F: Special Projects of National Significance (SPNS) also sheds light on groundbreaking interventions for improving care for people aging with HIV. It is important to note that people living with HIV are equally diverse as the community at large and often experience additional forms of discrimination based on their age, race, ethnicity, national origin, disability status, sexual orientation, gender identity, etc. By incorporating the needs of older people living with HIV across multiple sectors, state leaders and advocates can create more meaningful multisector plans on aging that help improve the quality of life for people of all ages living with HIV.

Recommendations

Here are recommendations based on the social and health needs of older people living with HIV:

1. Identify and reduce barriers to accessing services experienced by older people living with HIV across all sectors.

HIV stigma [7] and discrimination can have a significant impact on older people living with HIV, often making it challenging for them to access essential services. Due to fears of being seen at an "HIV clinic" or HIV organization, HIV-related stigma impacts both HIV prevention and care efforts. It discourages individuals from getting tested for HIV, leaving them unaware of their health status and delaying access to treatment. For those already living with HIV, stigma can affect medication adherence. Taking daily medicine can serve as a constant reminder of their diagnosis and amplify feelings of isolation or shame. Addressing stigma is essential to improving both HIV testing rates and sustained care for people living with HIV. Unfortunately, stigma impacts all levels of society, including policy development and implementation from state and local governments responsible for setting public policies down to local service providers. HIV stigma and discrimination can create barriers to accessing services — for example, using outreach materials that use language that reinforces negative stereotypes about people with HIV — and this can lead to people aging with HIV not receiving the care and support they need to manage their health effectively. As a result, multisector state plans must include proactive measures aimed at reducing these barriers as highlighted in the CDC's Let's Stop HIV Together (Together) campaign. An effective way to dismantle stigma is by providing comprehensive training to state agency leadership and staff. The training equips them with accurate HIV information and inclusive language resources (see the NIAID HIV Language Guide) to ensure they can offer comprehensive services to older people living with HIV. For more information about available training opportunities, please visit the Regional AIDS Education and Training Centers.

2. Explore sectors like Transportation, Labor, Housing, and others for opportunities to increase HIV inclusion.

The needs of older people living with HIV are often highlighted in the strategic plans of the Public Health and Human Services sectors, which are good places to start. As explained earlier, however, the needs of people aging with HIV span across sectors and should be reflected in multisector plans on aging.

Transportation is essential for older people living with HIV. Access to transportation can ensure that they reach medical appointments, access social support, and maintain social connections with family and friends within their communities. State leaders and advocates can increase HIV inclusion in transportation by providing affordable and accessible transportation options for older people living with HIV and coordinating with Ryan White funded organizations. This can include offering discounted or free transportation services (especially when accessing medical care) and partnering with transportation companies to provide specialized services.

Labor is another sector that plays a critical role in the lives of people living with HIV. Employment can provide financial stability and improve overall well-being. Older people living with HIV, however, may face employment discrimination based on HIV stigma despite federal protections under Section 504 of the Rehabilitation Act. State leaders and advocates can increase HIV inclusion in labor by developing policies and programs that protect the rights of people living with HIV in the workplace. This can include creating anti-discrimination policies and providing training for employers on HIV-related issues. Additionally, promoting HIV inclusion in employment opportunities and training programs for older people, like the Senior Community Service Employment Program, can help increase financial stability and improve the overall quality of life for older people living with HIV. For more information about the employment needs of people living with HIV, please visit the National Working Positive Coalition.

Access to safe and affordable housing is essential for the health and well-being of older people living with HIV. For more information and data on the housing needs of people living with HIV, see the Housing Opportunities for Persons With AIDS (HOPWA) Program and the National HIV/AIDS Housing Coalition. State leaders and advocates can increase HIV inclusion by creating policies and programs that provide affordable housing options for older people living with HIV. This can include partnering with housing authorities and community-based organizations to provide affordable housing options with supportive services, creating housing vouchers for people living with HIV, and providing financial assistance for housing-related expenses. Additionally, creating housing options that are

designed for aging-in-place can help older people with HIV maintain their independence and improve quality of life.

Public education has a vital role to play in addressing the needs of older people living with HIV. As the number of older people living with HIV continues to increase, schools and universities must provide education and training to healthcare and social service professionals to ensure they are equipped to meet the unique needs of the community. This can include training on age-related health issues for HIV care providers to reduce ageism and HIV stigma, as well as training on the needs of people living with HIV for aging service providers. In addition, education programs can help to raise awareness among older people themselves about the importance of HIV testing, treatment, and prevention — as well as sexual health. Local HIV organizations can often provide a speaker to provide this education.

3. Involve older people living with HIV and organizations serving the community in the planning process.

States should understand that the HIV community has a deep, rich history of demanding "Meaningful Involvement of People living with HIV/AIDS" as a process of keeping people living with HIV central to the creation and determination of the policies, funding, services, research, and initiatives. The state leaders responsible for guiding the development of multisector plans on aging do not have to be the experts on aging with HIV. People living with HIV are the experts who are best positioned to provide input on policies that impact their lives! There are also HIV/aging and policy experts at the national, state, and local levels who would welcome the opportunity to be a part of the state's planning process. These experts can be identified through HIV service providers and organizations in your state. We highly recommend that you reach out to the leadership of your state's Ryan White HIV/AIDS Program (RWHAP) grant program and/or local LGBTQ+ centers or organizations.

Recommendations

Here are recommendations based on the social and health needs of older people living with HIV:

1. Host listening sessions, town halls, key informant interviews, or focus groups that elevate the voices and needs of older people living with HIV in partnership with local HIV organizations.

It is important to have both qualitative and quantitative data to understand the needs of the most vulnerable members of the HIV/aging community. Qualitative data can help states develop targeted strategies, policies, and interventions that are specific to the needs of this community. Listening sessions, town halls, key informant interviews, or focus groups with standardized protocols and prompts can help gather nuanced information about quality of life and social determinants of health (SDOH) domains. When conducting these sessions, it is important to ask questions about what is working well, as well as what is not working, to avoid a deficit-based approach. This will give states a better understanding of what has been successful in the past, and what can be expanded upon in the future across various domains and sectors.

As states consider utilizing listening sessions, town halls, or focus groups, it is important to collaborate with older people with HIV and local HIV organizations that already serve people living with HIV. These local organizations can assist with recruitment and help guide the conversations in ways that are inclusive while maintaining confidentiality.

2. Invite leaders from HIV organizations to be part of committees and subcommittees.

State leaders should invite older people living with HIV in addition to leaders and experts on HIV/aging to serve on planning committees and subcommittees when developing multisector plans on aging for several reasons. These subject matter experts can provide valuable insights into the unique challenges and needs of older people living with HIV. By including people with HIV in the planning process, state leaders can ensure that the needs of this community are adequately addressed in the plan and help build trust and confidence among people aging with HIV. When leaders and experts engage in the planning process, it sends a message to people of all ages living with HIV that their voices and concerns are being heard and taken seriously.

Organizational and individual capacity limits can pose a challenge for organizations representing people with HIV to participate effectively in planning committees and similar initiatives. These organizations may have limited resources, staff, and expertise to engage in such activities. The same may also apply to individual leaders and advocates of those aging with HIV. Therefore, states need to consider how to support their participation in planning and decision-making processes. This may include providing training and technical assistance, offering funding and resources (such as stipends and transportation support), and creating opportunities for collaboration and networking with other organizations and stakeholders. Additionally, holding meetings or gatherings in spaces that are familiar and convenient for the older HIV community can foster a sense of safety and encourage participation. Such settings can make it easier for individuals to attend and contribute, ensuring more inclusive and effective discussions. Holding meetings or gatherings virtually can also make them more accessible for people who have limitations due to mobility. By prioritizing the involvement of people living with HIV and HIV organizations in these efforts, states can ensure that the voices and perspectives of this community are accurately represented and considered fairly in policy and program development.

3. Provide examples of successful HIV/aging programs and services.

States can highlight successful examples of HIV inclusion in existing state plans to demonstrate the feasibility and effectiveness of such initiatives. For instance, look for examples in State Plans on Aging for efforts to create inclusive services and programs for older people living with HIV because this is an Older Americans Act requirement. States are required to collect data on the needs of people aging with HIV, conduct outreach to this community, and evaluate the effectiveness of aging services in meeting their needs. For any new state plan on aging starting on or after October 1, 2021, states must describe plans and include objectives and the measures (data elements and sources) that the state unit on aging will use to demonstrate progress towards serving older people living with HIV. [8] Leaders of multisector plans on aging should also turn to their state's Integrated HIV Prevention and Care Plan, which is a requirement of the Ryan White HIV/AIDS Program (RWHAP) Part B grant program. Housing plans may already emphasize the need for affordable housing options and increased access to housing programs for people living with HIV (see the Housing Opportunities for Persons With AIDS (HOPWA) Program). By highlighting successful HIV inclusion in existing strategic plans, states can create a blueprint for other state agencies to follow — improving the lives of older people living with HIV across the United States.

Examples of Plans on Aging from Across the Nation

As mentioned earlier in this tool, leaders involved in developing and updating multisector plans on aging can turn to other plans for examples of HIV inclusion.

Illinois – State Plan on Aging

Strategy 2.1c: Engage in ongoing discussions through the Aging Network and ensuring openings on IDoA advisory councils committees—using lessons from ongoing active engagement described in Strategy 2.1b—and modify in response programming, funding, resources, and partnerships to better reach and meet their needs of such groups as:

- **Older adults living with HIV**, with a focus on reaching those who have also faced injustice and discrimination and may not trust public systems.

Strategy 7.4g: Continue to provide Ombudsman services to and collect data on individuals in the community who are receiving services under the following Waivers: Persons who are Elderly, Persons with Disabilities, Brain Injury, **Persons with HIV or AIDS**.

Indiana – State Plan on Aging

Strategy 2.1(e): Partner with the Indiana Department of Health, Division of HIV/STD & Viral Hepatitis to share information and coordinate opportunities for **older adults living with HIV/AIDS** to access services to support health, well-being, and long-term care needs.

Nebraska – State Plan on Aging

Strategy 29: Promote Health Promotion and Disease Prevention programming that serves **older adults living with HIV/AIDS**, as well as caregivers of older adults.

New Hampshire – State Plan on Aging

The Bureau of Elderly and Adult Services (BEAS) has started a connection with the NH Ryan White CARE Program. The Ryan White CARE Program provides a network of medical care, as well as, providing support for the identified needs of **people living with HIV**. The goal of this partnership is to enhance our efforts to bring our Chronic Disease & Self-Management Evidenced-Based programs to our older adult HIV/AIDS community in NH.

Strategy: Improve access to care for the LGTBQ+ community and elevate inclusivity within BEAS staff and partnering agencies by promoting training and educational opportunities by leveraging LGBT and **HIV Resources**, and the National Resource Center on LGBT Aging.

North Carolina – Advancing Equity in Aging: A Collaborative Strategy for NC

Strategy: Provide training on LGBTQ+ and **HIV+ rights and protections** to aging service providers and staff of long-term care facilities in partnership with the State Long Term Care Ombudsman Program, Legal Assistance providers, and LGBTQ+ and **HIV+ organizations**.

Strategy: In partnership with the UNC School of Social Work, develop LGBTQ+ and **HIV+ inclusive client rights and responsibilities** to be issued to recipients of care in all settings and made publicly available online.

Strategy: Encourage the aging network to engage in outreach and co-host programming with local LGBTQ+ organizations and **HIV providers**.

Strategy: In partnership with SAGE USA and local partners, prepare, publish, and disseminate educational resources about available services and resources for **people living with HIV** through partnerships with **HIV service providers** and for LGBTQ+ older adults with LGBTQ+ organizations.

Oklahoma – State Plan on Aging

Objective: Increase awareness of available resources and services for **older adults living with HIV/AIDS**.

Strategy: Partner with the Oklahoma State Department of Health and other community partners to disseminate information about services and resources for **people with HIV/AIDS to AIDS Service Organizations (ASOs)**.

Strategy: Provide training to AAAs and providers about **HIV/AIDS** and its prevalence in older Oklahomans.

Oregon – State Plan on Aging

Objective 1.4: Increase public knowledge, and knowledge among professionals serving older adults, of services and supports available for all older adults, with emphasis on reaching communitys in greatest economic and social need (with particular attention to **older adults living with HIV/AIDS**, Holocaust survivors and those at risk for institutional placement).

Objective 3.1: Enhance data collection and program evaluation to be inclusive of all communitys who are not currently adequately served by Oregon's aging system, including LGBTQIA2S+, Native American elders and **older adults living with HIV/AIDS**. (Note: Data collection will not include questions about a person's HIV/AIDS status.)

Objective 3.4: Strengthen ADRC capacity to reach older adults in rural areas, those who speak languages other than English, LGBTQIA2S+ older adults, Tribal elders and **older adults living with HIV/AIDS**. Focus on intersectionality and increasing service capacity in rural/frontier areas.

Strategy: Using available data, and in collaboration with specific community organizations and service providers, identify disparities in utilization of OAA funded health and wellness programs among older adults with the greatest social and economic needs, with particular emphasis on identifying disparities of **older adults living with HIV/AIDS**.

Texas – State Plan on Aging

Objective: Increase awareness of available resources and services for **older adults living with HIV/AIDS**.

Outcome: OAAA, AAA, and ADRC staff are aware of information and data sources available for **older adults living with HIV/AIDS**.

Measure: Host annual meetings (at least three) with HHSC and the Department of State Health Services (DSHS) to share information about services and resources for **older adults living with HIV/AIDS**.

Measure: Coordinate with DSHS to offer annual presentations (at least three) for AAAs and ADRCs to share information on available resources related to **older adults living with HIV/AIDS**.

Virginia – State Plan on Aging

Strategy: Deliver CRIA (referrals, information, and assistance) in a manner that is culturally and linguistically appropriate and trauma-informed regardless of race, ethnicity, gender, disability, religion, sexual orientation, **HIV/AIDS status**, or socioeconomic status.

Strategy: Collaborate with the Virginia Department of Health in support of the **Integrated HIV Prevention and Care Services Plan** to share information about OAA services with **older Virginians with HIV**.

Wisconsin – State Plan on Aging

Serving older adults living with HIV/AIDS
During the State Plan period, BADR will expand its collaborative relationship with the WI Division of Public Health's **HIV/AIDS program** within the Bureau of Communicable Disease (BCD), to better develop both programs' and to establish collaborative partnerships at the statewide level. Specific outcomes will include enhanced aging program and referral information on the BCD web pages and other resources; and enhanced **HIV/AIDS program and referral information** on the BADR web pages and other resources.

Additional Planning Resources

Navigating HIV Challenges in Aging: A Call for Inclusive Policies, Generations American Society on Aging

Equity Tool, California Master Plan for Aging Equity Work Group

Targeted Universalism: Policy & Practice, Othering and Belonging Institute, University of California, Berkeley

Aging & HIV: An introduction to legal issues facing people living and aging with HIV, The Center for HIV Law and Policy

Demystifying the Older Americans Act for Older People Living with HIV, SAGE

Better Integration Between HIV and Aging Systems is Critical, Older adults with HIV have unique needs that require focused attention, Kirk Grisham and Jeffrey S. Crowley, for O'Neill Institute Center for HIV and Infectious Disease Policy

The Reunion Project

National Resource Center on LGBTQ+ Aging

The Intersection of HIV, Aging, and Policy: A Critical Update

Work Cited

[1] Centers for Disease Control and Prevention. Estimated HIV incidence and prevalence in the United States, 2018–2022. HIV Surveillance Supplemental Report 2024;29(No. 1). https://www.cdc.gov/hiv-data/nhss/estimated-hiv-incidence-and-prevalence.html. Published May 2024. Accessed October 2024.

[2] https://www.hiv.gov/hiv-basics/living-well-with-hiv/taking-care-of-yourself/aging-with-hiv

[3] WING E. J. (2017). The Aging community with HIV Infection. Transactions of the American Clinical and Climatological Association, 128, 131–144.

[4] Some states use the term "masterplan on aging" while others use the more culturally responsive and better descriptive term "multisector plan on aging."

[5] https://health.gov/healthypeople/priority-areas/social-determinants-health

[6] Menza TW, Hixson LK, Lipira L, Drach L. Social Determinants of Health and Care Outcomes Among People With HIV in the United States. Open Forum Infect Dis. 2021 Jun 22;8(7):ofab330. doi: 10.1093/ofid/ofab330. PMID: 34307729; PMCID: PMC8297699.

[7] According to the CDC, HIV stigma is negative attitudes and beliefs about people with HIV. It is the prejudice that comes with labeling an individual as part of a group that is believed to be socially unacceptable.

[8] State Unit on Aging Directors Letter #01-2021, U.S. Administration for Community Living.