MOVING AHEAD TOGETHER

A Framework for Integrating HIV/AIDS & Aging Services

Moving Ahead Together is an initiative of Grantmakers In Aging that seeks to create closer connection, coordination, and expertise sharing between the HIV/AIDS services network and the aging services network with the goal of improving the lives and health of older people living with HIV/AIDS. This PDF offers a condensed outline of a full framework of recommendations for pursuing those goals. Find the complete document and learn more about the initiative at www.GIAging.org/HIV-aging.

Focus Area #1: COMPLEXITIES AND CHALLENGES	
Issue #1: The epidemic has changed over time.	• The survival rate is much improved. • Demographics have changed. • The age profile has changed dramatically. • Geographic distribution has shifted.
Issue #2: Certain groups bear a disproportionate burden.	• Racial disparities are high. • Black women face disproportionately high rates of infection. • Transgender older women face high risk of infection, stigma, and isolation. • Targeted HIV services for older women are rare. • Older people are more likely to have late-stage HIV at time of diagnosis. • Older people and their medical providers underestimate their risk.
Issue #3: Stigma perpetuates discrimination and creates obstacles to care and support.	• Multiple forms of stigma apply. • HIV stigma is reinforced by lack of community and provider understanding. • Misperceptions about HIV infection abound. • Social and racial justice concerns are common. • Discomfort in accessing aging services remains an issue for older people living with HIV.
Issue #4: Location matters; most services are local.	• Small towns and rural places may have different needs and resources than urban centers. • Communities' ability to obtain public funding or partially self-fund varies significantly. • Virtual support groups and professional services delivered by telehealth can expand options but OPLWH's access and capacity to use technology varies.

Issue #5: One size does not fit all in program design.	• Diversity among OPLWH may require extra creativity in creating services. • Differences matter; but scarce resources can make customizing or expanding services challenging. • Experience matters; long-term survivors' needs differ from those of older people newly diagnosed. • Even successful programs may not be easily replicated.
Issue #6: Underestimating the challenge and overestimating progress.	• "A manageable chronic disease" • Less public focus. • Multiple co-morbidities and accentuated aging are part of the experience. • Recruiting new HIV providers is getting harder and older specialists are starting to retire. • Overtaken by COVID-19?

Focus Area #2: INTEGRATING AND IMPROVING CARE AND SERVICES

Focus Area #2A: CORE PRINCIPLES

Issue #1: Health equity principles should inform HIV and aging programs and care.	• Acknowledge the health disparities, racial and social inequities, stigma, marginalization, and discrimination that many OPLWH experience. • Leverage the social determinants of health. • Bring a social and racial justice lens to HIV and aging programming and advocacy. • Employ a values-based approach to build intergenerational, intersectional, and multi-sector appeal.
Issue #2: Promote person-centered care by connecting HIV, aging, and social care providers.	• Offer or co-locate complementary services where possible. • Establish systems to increase communication, expertise sharing, and referrals between HIV, geriatric/primary care (PC) providers, and social services. • Learn from one-stop-shop integration used in many Ryan White programs. • Leverage the trust that OPLWH feel with providers and settings in their "comfort zones" when adding, integrating new services.

Focus Area #2B: MEDICAL CARE

Issue #1: Help primary care providers and geriatricians build their knowledge of HIV issues.	• "Could it be HIV?" • Create and disseminate educational resources and professional development opportunities to help geriatrics and PC providers build HIV expertise. • Increase health care professionals' knowledge of the potential for polypharmacy in patients living with HIV and other conditions. • Encourage HIV-related Continuing Medical Education (CME) curriculum, mentoring, attendance at conferences and specialized trainings.

Issue #2: Include sexual health in primary and specialty care for older adults.	• Encourage and support regular taking of sexual history from older adults. • Encourage, support, and provide appropriate training for providers on "difficult conversations" about older adult sexuality and HIV, potential risk factors, HIV testing, knowing HIV status, and prevention options. • Promote geriatric and PC provider and staff awareness of PrEP and PEP medication and U=U.
Issue #3: Build primary care providers' and geriatricians' cultural competency on HIV issues.	• Acknowledge and work to eliminate stigma in health care that can exacerbate OPLWH's fear of being rejected or "outed." • Promote marketing (signage, handouts, online) that indicates that OPLWH and sexual minorities and gender diverse people are welcomed and served. • Include staff (e.g., schedulers, receptionists, medical assistants, office and facilities staff) in cultural competency training. • Seek guidance on policies and practices from OPLWH where possible.

Focus Area #2C: MENTAL AND BEHAVIORAL HEALTH CARE

Issue #1: Improve access to mental health (MH) and behavioral health (BH) care.	• Strengthen awareness of HIV/aging issues among MH and BH providers. • Streamline referrals between MH, BH, and medical services. • Treat behavioral health problems to improve treatment adherence and clinical outcomes.
Issue #2: Expand work on HIV-specific concerns with cognitive decline, dementia, and Alzheimer's Disease.	• Increase screening, treatment, and interventions for mild forms of cognitive impairment commonly seen in OPLWH. • Increase awareness and research on HIV-associated neurocognitive disorders. • Develop, increase, and support therapeutic and caregiving options.
Issue #3: Incorporate principles of trauma-informed care.	• Recognize the history of trauma among OPLWH. • Help OPLWH remain in care by raising providers' trauma awareness.
Issue #4: Recognize and address the destructive power of stigma.	• Educate providers that multiple types of stigma exist that affect OPLWH. • Recognize that fear of rejection or being "outed" in non-HIV settings deters many OPLWH from seeking care, jeopardizing health. • Seek guidance on policies and practices (e.g., communications) from OPLWH.
Issue #5: Prepare community-based support groups to assist OPLWH.	• Offer education, coaching on serving OPLWH to community-based groups. • Help OPLWH connect with groups that are well prepared to welcome people living with HIV.

Focus Area #2D: SOCIAL/PSYCHOSOCIAL SUPPORT	
Issue #1: Target social isolation.	• Recognize the destructive power of social isolation as a driver of poor mental and physical health in OPLWH. • Promote social opportunities, support groups, access to online peer support. • Recognize that some support and/or facilitation may be required. • Recognize the importance of caregiver support.
Issue #2: Address social determinants of health in programming.	• Emphasize economic insecurity as a critical issue for many OPLWH. • Include programs such as supportive housing, subsidized housing, transportation, food security, legal counseling, and job training and placement as part of a holistic approach. • Get HIV and aging issues onto the agenda of social service providers. • Expand patient education and assist with program navigation. • Include disaster preparedness and response to increase program resiliency.
Issue #3: Recognize diversity in identifying needs and designing programs.	• Explore program segmentation by group identity; lived experience; racial, ethnic, and socioeconomic backgrounds; experience; gender; and sexual orientation. • Be aware that age-specific groups may be preferred. • Be guided by OPLWH.
Issue #4: Lack of social support often includes a lack of caregivers.	• Support informal caregiving programs. • Promote Advance Care Planning for people aging with HIV, including creating living wills and selecting health care decisionmakers.
Issue #5: Support peer-led groups (or make skilled facilitation available).	

Focus Area #3: THE WAY FORWARD	
Focus Area #3A: POLICY	
Issue #1: Add aging issues to the Ending the HIV Epidemic (EHE) plan.	• OPLWH should be considered an EHE special needs population. • Expand focus to include people living with HIV, rather than focusing only on preventing new infections. • Existing focus on prevention should also explicitly include older people's risk of contracting HIV and access to testing. • Explore ways to allow OPLWH to make important contributions to EHE pilot programs. • Advocate for including the needs and concerns of OPLWH in all federal, state, and local plans and initiatives to end the HIV epidemic.

Issue #2: Reconsider age specificity in program eligibility: Is anyone "too young" to receive aging services?	• Explore and expand access to OAA programs that do not have age-restrictions (such as support for early-onset dementia). • Re-imagine eligibility for aging services (e.g., nutrition programs, behavioral health) based on need, functional status, or risk of institutionalization, rather than age. • Take advantage of less rigid age restrictions on funding for aging research, particularly on issues of longitudinal change or disease course.
Issue #3: Explore opportunities within the Older Americans Act (OAA) and OAA reauthorization process.	• Pursue designation of OPLWH as an OAA "population of greatest social need." • Explore other OAA funding streams, programs for which OPLWH are or could be eligible. • Learn from, build on related policy successes at the state level.
Issue #4: Prepare Medicare to serve a growing population of beneficiaries living with HIV.	• Require Medicare to support OPLWH with enrollment and transition into the program. • Update the Ryan White program to ensure better integration with Medicare (and to coordinate when that is allowed) to prevent OPLWH from "aging out" of trusted services. • Increase Medicare's awareness and data on the needs of OPLWH as an emerging Medicare population, including medication costs and co-morbidities. • Maintain status of antiretroviral drugs as a "protected class" under Medicare Part D. • Encourage Medicare to standardize benefits and expand funding for HIV case management services in diverse settings. • Add HIV-related outcomes and data collection to Medicare performance measures, including gender identity and sexual orientation. • Add HIV care quality measures to nursing home data collected and reported to Medicare. • Educate OPLWH about the Welcome to Medicare benefit; help providers maximize its utility. • Seek opportunities to maximize the Medicare Annual Wellness Visit for OPLWH. • Prepare peer support programs within the aging services network to assist OPLWH entering Medicare.
Issue #5: Address Medicaid's important role in serving OPLWH and its multiple state-by-state challenges.	• Strengthen coordination between Medicare and Medicare to improve care of dually eligible OPLWH. • Make it easier, and provide help for beneficiaries to transition into Medicaid from other programs, including private insurance. • Ensure that Medicaid programs that use managed care to provide long-term services and supports (LTSS) are prepared for the needs of OPLWH. • Add HIV-related outcomes to Medicaid performance measures to incentivize good care. • Support Medicaid expansion as a means of addressing social determinants of health for OPLWH. • Oppose Medicaid block grants, cuts, and eligibility changes that would reduce services.
Issue #6: Strengthen protections under Social Security Disability (SSI).	• Support legal services providing for review, appeals and advocacy groups. • Provide support for job readiness, re-training, and placement services for people who are ruled able to work and whose SSI is withdrawn.

Issue #7: Leverage role of regulators to integrate and strengthen systems.	• Encourage accrediting bodies (e.g., HRSA) to include non-HIV specific outcomes such as advance care planning and completion of Medicare Wellness exams in HIV quality measures.
Issue #8: Recognize, address the need for options in long-term services and supports (LTSS).	• Add HIV and LGBTQ education to the industry's existing cultural competence training, workforce development, and trauma-informed care. Include medical personnel and volunteers. • Raise provider and staff awareness and preparedness on challenges that some OPLWH live with, such as substance use. • Pursue state-based approaches to discrimination protections for OPLWH in long-term care settings, building on recently passed Illinois model. • Expand alternatives to nursing home placement for OPLWH, including aging in community, in-home care, low-income housing, and supportive housing. • Advocate for expansion of housing and housing assistance under the Housing Opportunities for Persons with AIDS Program (HOPWA). • Recognize that economic insecurity and lack of savings put many LTSS options out of reach for some OPLWH. • Explore options for an HIV-related program on the PACE (All-Inclusive Care of the Elderly) model.
Issue #9: Address legal discrimination and criminalization concerns.	• End criminalization of HIV exposure or additional penalties for committing other crimes while HIV positive. • End discriminatory practices that exclude people living with HIV from purchasing life and disability insurance.

Focus Area #3B: INSPIRATION AND REPLICATION

Issue #1: Ensure broad-based exploration and learning and a strength-based approach.	• Build on a tradition of engaged patients and self-advocacy to improve care of OPLWH. • Maximize the unrealized potential for better coordination in both sectors. • Identify and pursue common ground between HIV and aging sectors for future work.
Issue #2: Seek to turn the relative newness of aging with HIV into an asset.	• Acknowledge the newness of the field and relative lack of program examples, while working to address that; make this an advantage by cultivating discovery and innovation. • Use example of flexibility and reduced funding restrictions in many COVID-19-related programs to show that important work is not exclusively evidence-based.
Issue #3: Listen and learn from the resilience, courage, and authentic voices of OPLWH.	