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

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#### 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. |
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.

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.

An initiative of Grantmakers In Aging