Addressing the Health Care and Social Support Needs of People Aging with HIV

Technical Expert Panel Executive Summary

HRSA
Ryan White HIV/AIDS Program

The Health Resources and Services Administration (HRSA) HIV/AIDS Bureau (HAB), which oversees the Ryan White HIV/AIDS Program (RWHAP), convened a Technical Expert Panel in November 2020. It explored the health care and social support needs of RWHAP's aging population, with a focus on the barriers to and strategies for providing services. Twenty panelists representing people with lived experience, federal partners, state and local health departments, health care providers, researchers, and peer support organizations took part in the discussions.

This Technical Expert Panel (TEP) Executive Summary includes the following sections:

- Considerations for providing HIV medical, psychosocial, and support services to people aging with HIV;
- Opportunities for improving health care services and social support for people aging with HIV;
- How RWHAP recipients can improve services for people aging with HIV; and
- Workforce issues.

The Ryan White HIV/AIDS Program: Serving People Aging with HIV

- In 2019, almost half (46.8 percent) of RWHAP clients were aged 50 and older, the majority of these clients were aged 50–59 years, 28.5 percent of all RWHAP clients. Nearly 10.0 percent of RWHAP clients were aged 60–64, and 8.5 percent were aged 65 and older.
- The majority of older RWHAP clients are male, approximately 71.0 percent of clients aged 50 years and older.
- Almost 70.0 percent of these clients are from racial and ethnic minority populations, the vast majority being Black/African American.

Considerations for Providing HIV Medical, Psychosocial, and Support Services to People Aging with HIV

Panelists identified issues that relate to aging in general, aging issues specific to people with HIV, and the provision of services to people aging with HIV.

HIV-Related and Age-Related Stigma. Almost 40 years into the HIV/AIDS epidemic, HIV-related stigma is still a barrier to care for people with HIV. Stigma toward people who are older, also known as ageism, on the part of the general public and service providers can influence a person's willingness to access and remain in care. Negative preconceptions exist about older adults in terms of their ability to carry out the activities of daily life and their ability to make decisions related to their care and life.

Perceptions and Realities About Aging. Panelists discussed that to effectively serve older individuals, whether they are HIV positive or not, clinicians must first understand each individual's attitude toward aging. Some people, no matter their age, resist accessing services for older patients. Their perception is that they do not feel old and do not want to be viewed as old. Clinicians and other service providers need to take into consideration patients' attitudes toward aging, as well as their physical and mental health and social support needs, and not base assessments strictly on age.

Increasing Demands for Care as the United States' Population Ages. Panelists emphasized that the United States lacks the capacity to meet the health and social service needs of an aging population. Most significantly, there is a shortage of geriatricians. Primary care physicians lack the skills and time to address the needs of aging patients and do not routinely conduct the necessary screenings for this population. Panelists discussed that although some RWHAP clients do see a geriatrician, HIV and geriatric care may not be well coordinated. Also, people aging with HIV need access to additional specialists (e.g., cardiologists, endocrinologists, rheumatologists).

Diversity of People Aging with HIV. The population of people aging with HIV is incredibly diverse. These differences can affect the care and services they want and need.

- **Age-Related Differences.** For the most part, the needs of people in their 50s are different from those of people in their 60s, 70s, and beyond. However, as panelists observed, age is not the only consideration. Service providers should assess each patient's circumstances. It was noted that accessing services may be a major challenge for people in their 50s. Many services that older people access (e.g., Medicare, community-based support services) have specific age-related eligibility criteria (e.g., 60 years).
- **Long-Term Survivors.** People who were diagnosed with HIV in the 1980s or 1990s have lived with the virus for many years. Antiretroviral treatment (ART) can result in serious long-term side effects. Living with HIV for many decades also can have a significant impact on mental health.
- **Newly Diagnosed.** People who receive a diagnosis of HIV in their 50s (or older) must learn about the HIV-related system of care and available support services. They also must consider how to disclose their status to others (e.g., family and friends, sexual partners) and learn about sexual health and HIV prevention.

Isolation, Loneliness, and Lack of a Social Support Network. Research indicates that isolation and loneliness are associated with both physical and mental health issues, including cardiovascular disease, stroke, and depression.[1,2] Mental health support can reduce isolation and loneliness. Panelists emphasized that providing social support for people aging with HIV is an important priority for this population. Given that this population may face challenges in terms of mobility, access to technology (e.g., devices, the internet) and training in how to use it, transportation, and financial resources, it is necessary that service providers offer opportunities to socialize. Buddy programs, a successful strategy in the early days of the HIV epidemic, is one approach. Panelists also suggested that organizations run by and for people aging with HIV can provide social opportunities.

Access to Care. Beyond the financial ability to pay for services and age-related eligibility criteria, both of which may limit access to care, other factors can affect the ability or willingness of people aging with HIV to access services. Access to care can be improved by creating a welcoming environment where people feel comfortable receiving care; providing transportation; ensuring that facilities and services are accessible to people with physical and/or sensory disabilities; and providing access to electronic devices, the internet, and other technology.

Quality of Life. According to panelists, measuring quality of life is not reflected in the metrics related to the HIV epidemic and is not included on the HIV continuum of care. Quality of life affects both physical and mental health, which affects the likelihood of remaining in care and adhering to treatment.

Opportunities for Improving Health Care Services for People Aging with HIV

Panelists discussed multiple ideas for improving health care services for people aging with HIV:

- Partner with federal, state, and local organizations that provide services to older Americans. These can include Area Agencies on Aging, which are public or private nonprofits designated by states to address the needs and concerns of older adults. State and local governments also have Offices of Aging. The U.S. Department of Health and Human Services' Administration for Community Living

[1] Health Resources and Services Administration. 2019. *The Loneliness Epidemic.* Available at hrsa.gov/enews/past-issues/2019/january-17/loneliness-epidemic. Accessed December 2, 2020.

[2] Holt-Lundstad J. 2017. "The Potential Public Health Relevance of Social Isolation and Loneliness: Prevalence, Epidemiology, and Risk Factors." *Public Policy & Aging Report.* 27(4): 127-130.

advocates across the federal government for older adults, people with disabilities, and families and caregivers.

- Involve people aging with HIV as members of the care team. Provide training for clinicians (e.g., how to partner effectively, listening skills) and the patient (e.g., health literacy, advocacy skills).
- Include peers in the provision of care, whether acting as a member of the care team (e.g., nurse, patient navigator), coordinating referrals, providing social support, or providing retention or adherence support. Panelists emphasized the importance of professionalizing these roles and providing compensation.
- Coordinate health care through such strategies as interdisciplinary care teams; the collaborative care model that brings together primary care providers, care managers, and psychiatric consultants to provide mental health care; patient-centered medical homes; and co-location of services.
- Improve the screening for patients aging with HIV. Age-related screenings (e.g., frailty, cognitive function, elder abuse) should occur earlier for people with HIV (i.e., earlier than recommended for the general population) and integrated into primary care. The Medicare annual visit can serve as a model because it covers many of the domains important for this population. HAB has developed two resources focused on improving care for patients aging with HIV: *Optimizing HIV Care for People Aging with HIV: Incorporating New Elements of Care* and *Optimizing HIV Care for People Aging with HIV: Putting Together the Best Health Care Team*.

Opportunities for Improving Social Support for People Aging with HIV

Because of the importance of addressing loneliness and isolation in this population, panelists identified strategies for providing social support.

- ***Support groups*** (either in-person or via an online videoconferencing platform) provide an opportunity for people to connect with their peers and share experiences. Support groups should be tailored to specific needs (e.g., newly diagnosed, women, etc.). Support groups can focus on topics other than HIV. For example, people could get together for exercise or to support other healthy behaviors.
- ***Peer support,*** through HIV organizations or organizations for older adults, allows sharing "lived experience" and provides mutual support. Some programs focus on pairing peers by age; others follow an intergenerational model.
- ***Social organizations*** can help address isolation and provide social outlets. These organizations may be independent or operated through a larger organization. Many older individuals are interested in volunteer opportunities as a way of giving back to the community.
- Allow additional time for clinicians to address patients' complex needs (e.g., extended appointments).
- Dedicate referral staff (e.g., case managers, referral specialists) to identify appropriate services and to facilitate and follow up on linkage.
- Consultants (e.g., behavioral service consultants, pharmacists) can expand the range of services available to older patients.
- Provide additional support to patients, such as establishing monthly telephone check-ins or acting as a liaison between service providers. Members of the care team (e.g., nurses, case managers, peers) can carry out these activities.
- Facilitate access to services through home visits or by providing care in mobile vans.
- Facilitate access to housing and long-term care, which can be difficult to arrange for this population. Although long-term care is not an allowable expense under the RWHAP, many recipients develop links to organizations in their community to facilitate access for their clients. Panelists noted that many long-term care facilities and nursing homes are not welcoming to lesbian, gay, bisexual, transgender, and questioning (LGBTQ) individuals and people with HIV. It can be difficult to find housing partners, especially in rural areas. When forming partnerships, recipients should ensure that the providers will treat clients with respect.

How RWHAP Recipients Can Improve Services for People Aging with HIV

Panelists shared ideas on steps RWHAP recipients and subrecipients can consider to ensure that services are welcoming to this population and addresses their needs.

Planning. RWHAP Part A and Part B recipients are required to engage in jurisdiction-wide planning activities. Panelists stated that although many people aging with HIV are members of planning groups, their presence does not necessarily translate into these groups' focusing on the needs of that population. Panelists suggested integrating older adults through all planning group activities and creating space for older members to speak. Panelists emphasized that these members should be provided support to facilitate participation (e.g., transportation) and compensation, if possible.

Advisory Committees. Panelists suggested that agencies establish an advisory committee with patients (and staff, if appropriate). Identifying a staff person to coordinate this activity can help with recruitment and ongoing involvement.

Needs Assessment. Among RWHAP recipients, needs assessment activities take place at multiple levels. For Part A and Part B recipients, needs assessment examines needs across the jurisdiction. Panelists identified multiple ways to collect data for planning purposes, including town hall meetings with clients, providers, and researchers; focus groups; client satisfaction surveys (written, telephone, electronic);

assessment of HIV providers to determine their knowledge of aging issues; and assessment of geriatricians to determine their knowledge of HIV. Conducting such needs assessment activities as surveying staff and patients or convening focus groups can provide agencies insights into the needs of this population and areas for improving the delivery of services.

Normalize and Standardize Services for People Aging with HIV. Patients are more receptive when they perceive that services offered are standard protocol within the clinic (e.g., screenings, regular check-ins). Otherwise, they may feel they are being singled out for services they do not want or feel they need.

Track Care and Service Delivery. To ensure patients receive the care and services they need, carefully track service delivery, such as screenings completed, whether patients followed up on referrals, and what services were received. Regular follow-up confirms that patients remain in care or continue to receive necessary services.

Impact of COVID-19 on Services for People Aging with HIV

This TEP took place in November 2020, and panelists mentioned many of the changes in patient needs and service delivery that occurred because of the COVID-19 pandemic. Older adults and people with HIV are at increased risk for COVID-19. Panelists provided some examples of how COVID-19 has affected service provision.

- COVID-19 has increased the number of mental health issues for people aging with HIV (e.g., isolation, loneliness, anxiety).
- Most clinics implemented telehealth visits. However, telehealth presents a challenge for patients who do not own a device that allows the use of telehealth technology, lack access to the internet, or do not have the technical savvy to access telehealth services.
- Service providers found alternative ways to provide services and opportunities to socialize safely. (e.g., check-in phone calls)

Workforce Issues

Preparing the existing workforce to provide care and support to people aging with HIV is necessary. In particular, panelists emphasized the importance of interdisciplinary training and training all staff to ensure a welcoming environment where all staff understand the needs of this population. The panel noted the need to recruit new employees to the HIV workforce due to the approaching retirement of many current employees. Important training topics include cultural competency related to aging (especially for younger staff); assessing patient needs; medications (drug–drug interactions); trauma-informed care; and how to partner with patients.

Conclusion

As stated previously, more than half of RWHAP clients are aged 50 and older. It is important to ensure that services are in place as they continue to age. Among RWHAP clients aged 50 and older who are receiving RWHAP HIV medical care, 90 percent are virally suppressed, which indicates that the vast majority are engaged in ongoing care and adhering to antiretroviral treatment. Panelists noted that the RWHAP can be a model for providing geriatric care by coordinating with and building on services for older adults that are already in place.

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