

HIV & AGING POLICY ACTION COALITION (HAPAC) FAQ

WHAT IS DOES THE TERM 'LONG TERM SURVIVOR' MEAN?

Those who have been living with HIV since before the modern era of effective HIV drugs, or "highly active antiretroviral therapy" (HAART). They are sometimes known as pre-HAART LTS or "longest-term survivors." They acquired HIV when the condition was not yet treatable and often carried the stigma of a 'death sentence'/high mortality rates.¹

WHAT ARE SOME INITIAL GOALS OF HAPAC?

Advance State-Based Greatest Social Need Designations

- Include Long-Term Survivors as a Target Population in the 2019. Reauthorization of the Older Americans Act.
- Create model Long Term Care Bill of Rights legislation based on California's groundbreaking statute, with input from long-term survivors, policy experts and key ally organizations.

Long Term Care Bills of Rights

- Advance National Long-Term Care Bills of Rights and Cultural Competency Training Requirements.
- Create model Cultural Competency Training statute based on California's and Massachusetts's groundbreaking statutes, with input from long-term survivors, policy experts and key ally organizations.

¹ "Long-Term Survivors of HIV." *The Well Project*, The Well Project, 12 June 2019, www.thewellproject.org/hiv-information/long-term-survivors-hiv.

WHAT ARE SOME OF THE PRIORITY ISSUES CONCERNING HIV LONG TERM SURVIVORS (LTS) AND LGBT OLDER PEOPLE?

Health Issues

The U.S. Department of Health & Human Services (HHS) reports that, for long-term survivors, individuals living with long-term HIV infection exhibit many clinical characteristics commonly observed in aging: multiple chronic diseases or conditions, the use of multiple medications, changes in physical and cognitive abilities, and increased vulnerability to stressors. In fact, long-term survivors can present as a decade, or more, older than their biological age. Further, while effective HIV treatments have decreased the likelihood of AIDS-defining illnesses among people aging with HIV, HIV-associated non-AIDS conditions are more common in individuals with long-standing HIV infection. HHS notes that these conditions include cardiovascular disease, lung disease, certain cancers, HIV-Associated Neurocognitive Disorders (HAND), and liver disease (including hepatitis B and hepatitis C), among others.

Financial Issues

Adding to these challenges, many long-term survivors have faced the financial trauma of having cashed in their retirement savings and life insurance policies, with the expectation they wouldn't live to see another year, let alone another month. As a result many long-term survivors are living lives they didn't plan or prepare to live, without connection to families of origin and thin social support networks.

Employment Issues

Many long-term survivors have relied for decades on government-funded disability programs. And now, as they cycle off disability support and on to Social Security, they have scant work histories to justify more than a minimal social security check.

Housing Issues

On top of these already difficult financial challenges, many continue to live in progressive cities with skyrocketing housing and living costs like San Francisco and New York.

WHAT ARE HAPAC'S MAIN FOCUSES?

Public education about HIV and aging

HAPAC prioritizes educating lawmakers and the public about the fundamental issues around HIV and aging. First, that those who are institutionalized must be protected from discrimination based on their HIV and/or LGBT status and must have access to culturally competent care. Second, that those living in the communities in which they've always resided – and therefore hope to remain – can access the services and supports they require to remain independent and age in place.

Driving change at the state level

For those who are institutionalized, the HAPAC ensures that this population will have the most basic right to live free from discrimination and with access to culturally competent care. We educate and empower long-term survivors and their allies to drive support for the passage of state and federal long-term care bills of rights legislation, based on California's recent successful passage of this type of law. This critical legislation, which SAGE is now championing in New York State and the District of Columbia, would, among other things, ensure that long term care facilities and their employees cannot discriminate against residents based on their HIV status. HAPAC engages long-term survivors and their allies to drive support for the passage of state and federal, comprehensive, cultural competency training requirements for long term care institutions.