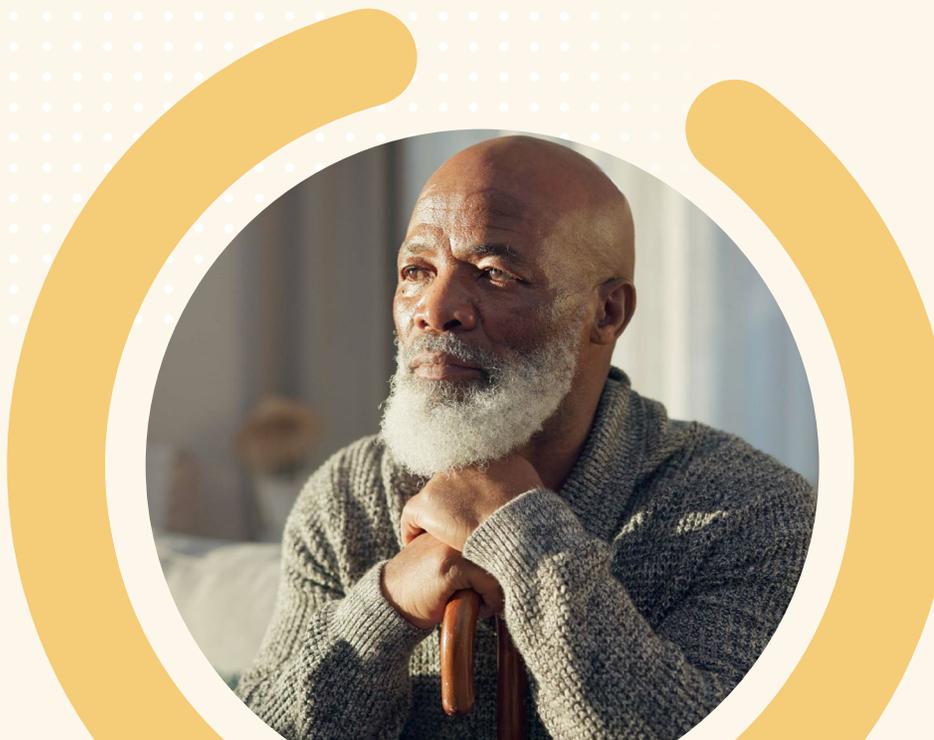
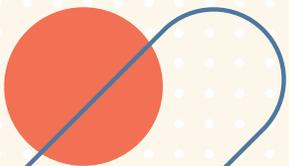
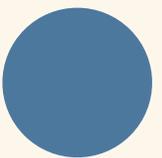


Aging & HIV

**AN INTRODUCTION TO LEGAL
ISSUES FACING PEOPLE LIVING
AND AGING WITH HIV**





CHLP: THE CENTER FOR HIV LAW AND POLICY

CHLP is an abolitionist legal and policy organization fighting to end stigma, discrimination, and violence toward communities that experience racial oppression, patriarchal violence, and/or economic divestment. We center our work in communities of people living with and deeply affected by HIV and other stigmatized health conditions, especially Black, brown, trans and/or queer, women, femmes, people who engage in sex work, use drugs, are disabled, living with stigmatized diseases, without housing, and/or are currently or formerly incarcerated. All of our work is firmly located within the larger abolitionist movement for real safety and liberation.

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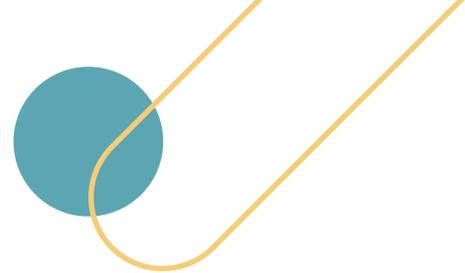
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“The number of Americans aged 65 and older is projected to increase from 58 million in 2022 to 82 million by 2050 (a 47% increase).”

THE U.S. CENSUS BUREAU¹

Introduction

The United States is generally not well prepared to address the issues facing the rapidly expanding population of older Americans. The country’s underfunded and overextended social services network leaves older Americans vulnerable to or experiencing housing and food insecurity coupled with mounting medical expenses. This network is also woefully underprepared to provide for the expansive needs of the 70% of People Living with HIV (PLHIV) who are projected to be over the age of 50 by the year 2030.²

Over the last 40 years, treatment advancements have lengthened survival rates for people who acquire HIV from months to decades, but the infrastructure for addressing their needs has not proportionately expanded. With access to healthcare and treatment, HIV is now a controllable, chronic condition. But People Living

By the year 2030, 70% of people living with HIV are projected to be over the age of 50.

and Aging with HIV (PLAHIV) have statistically higher rates of co- and multi-morbidities requiring extensive medical care. Some of these, such as HIV-associated Neurocognitive Disorder, can make aging in place, the goal for many aging people, difficult if not impossible.³ PLAHIV are also statistically more likely to be lower income, which can limit their decision-making power and healthcare options.⁴ Many PLAHIV not only have to contend with stigma and discrimination based on their serostatus, but their access to care and resources is impacted by anti-Blackness, racism, homophobia, transphobia, and ageism.

¹ U.S. Census Bureau, *2023 National Population Projections Tables: Main Series*.

² Health HIV, *State of Aging With HIV: Third Annual National Survey, 2023*, <https://healthhiv.org/positivelyaging>.

³ The term HAND, or HIV Associated Neurocognitive Disorder, has been coined to describe the spectrum of cognitive and dementia-causing issues faced by people aging with HIV. Deanna Saylor et al., “HIV-associated Neurocognitive Disorder: Pathogenesis and Prospects for Treatment,” *Nat Rev Neurol*. 12, no. 4 (April 2016): 234–48.

⁴ Mark Brennan-Ing et al., “Aging With HIV: Health Policy and Advocacy Priorities,” *Health Education & Behavior* 48, no. 1 (January 7, 2021): 5–8, <https://doi.org/10.1177/1090198120984368>; Paul Denning et al., “Communities in Crisis: Is There a Generalized HIV Epidemic in Impoverished Urban Areas of the United States?,” July 2010, https://www.law.berkeley.edu/files/DenningandDiNenno_XXXX-1.pdf.

The focus of this primer is to help PLAHIV identify and overcome the legal barriers to aging with dignity. It should serve as a tool to explain existing support systems and as a guide for advocates to identify where policies could be changed or created to provide for increased support. In addition to identifying barriers, it outlines information about legal protections and remedies like the Americans with Disabilities Act (ADA). And it is the first resource of its kind to address the statistical likelihood that many PLAHIV have had contact with the criminal justice system and may have criminal records that will impact their ability to access services and resources as they age.⁵

The focus of this primer is to help people living and aging with HIV identify and overcome the legal barriers to aging with dignity.

The primer is geared toward long-term HIV survivors (people who have been living with HIV for a decade or longer) who are now reaching or are over the age of 50 and are preparing to age with HIV. The information is also relevant to lifetime survivors or Dandelions (people who acquired HIV through vertical transmission and have been living with HIV their entire lives), and to the rapidly growing number of people who are acquiring HIV in their later years.⁶

Each section of this primer explores a different area of law that impacts PLAHIV:

1. Federal laws such as the Americans with Disabilities Act that protect PLHIV from discrimination and the agencies that can assist with remedying complaints.
2. The criminalization of PLHIV and the collateral consequences of criminal

legal system involvement and criminal records on PLAHIV.

3. The barriers to and remedies for protecting the power of PLAHIV to make decisions about their health and medical care.

Each section frames the issue and describes relevant laws, suggests avenues for self-advocacy, and recommends policy priorities for continued advocacy by and on behalf of PLAHIV.

This primer was designed to be accessible and informative for PLAHIV across the United States, however, that breadth of scope was also a challenge. Many of the issues addressed, such as criminal records and collateral consequences, are primarily governed by state laws that can vary widely. The primer deals with these issues generally, focusing on federal law and highlighting where differences in state law may matter. Interspersed throughout are vignettes that highlight issues in specific states to illustrate how state laws differ or to expand on key issues in that state. Please note that different states sometimes refer to the same legal concept using entirely different language or, more confusingly, the same language to refer to different legal concepts. For example, an expungement in Pennsylvania is not the same as an expungement in North Carolina because they address different types of criminal case outcomes.

People living with HIV deserve to age with dignity and to have that ability fully supported and funded by government resources. They deserve to have their rights protected in both public and private spheres and not face stigma and discrimination. This primer provides as much information as possible about ways that the law supports the ability of PLAHIV to age with dignity while highlighting some of the limitations and flaws of America's aging support systems.

⁵ M-J Milloy et al., "Incarceration of People Living with HIV/AIDS: Implications for Treatment-as-Prevention," *Curr HIV/AIDS Rep.* 11, (September 2014), <https://doi.org/10.1007/s11904-014-0214-z>.

⁶ There are unique challenges facing both of those groups that requires and deserves a dedication of resources to which this primer is a contribution.

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“So, if I’m dying from anything, I’m dying from homophobia. If I’m dying from anything, I’m dying from racism. If I’m dying from anything, it’s from indifference and red tape, because these are the things that are preventing an end to this crisis. If I’m dying from anything, I’m dying from Jesse Helms. If I’m dying from anything, I’m dying from the President of the United States...AIDS is really a test of us, as a people.

When future generations ask what we did in this crisis, we’re going to have to tell them that we were out here today. And we have to leave the legacy to those generations of people who will come after us.”

**VITO RUSSO
WHY WE FIGHT¹**

¹ Vito Russo, “Why We Fight,” ACT UP, May 9, 1988, <https://actupny.org/documents/whfight.html>.

Federal Antidiscrimination Laws and Remedies



ACT UP activist Vito Russo was diagnosed with HIV in 1985 and died in 1990 at the age of 44, when an HIV diagnosis was a likely death sentence with a life expectancy of a couple of years at most. With the advent of antiretroviral treatments, HIV is no longer a terminal condition but instead a manageable one. With access to effective treatment, people living with HIV can live long, healthy lives. Today, more than 50% of people living with HIV are age 50 or older. By 2030, more than 70% of people living with HIV will be over the age of 50.² This percentage will include long-term survivors who have lived with HIV for decades, as well as people who acquired it in their later years.

A large percentage of this cohort will likely be Black people, as well as gay men or men who have sex with men (MSM), because they are the groups most vulnerable to acquiring HIV. Between 300,000 and 400,000 older people living with HIV are men who have sex with men, and as of 2016, Black people made up 42% of new HIV diagnoses and 39% of all older people living with HIV.³ Black women, including Black trans women, make up a substantial percentage

of this group. Potentially, many in this cohort will be people who live with opioid use disorder. These characteristics — age, living with HIV, race, sex, etc. — are special categories known as “protected classes” that are subject to one or more federal laws that protect people from discrimination.⁴ Additionally, depending on where people live, many will be protected from discrimination under state as well as federal law.

In the context of these laws, discrimination does not necessarily require negative or unfair treatment; it can be, instead, “different treatment for similarly situated parties, especially when no legitimate reason appears to exist.”⁵ For example, if a person is treated differently from other applicants at a job interview because of the person’s HIV status, or is made to answer different questions about their health and ability to perform job duties, it is textbook discrimination. But if one can show that they are a member of a “protected class,” an identity category addressed by an antidiscrimination law, they can use these federal statutes for protection or redress, and potentially pursue compensation for damages suffered.

² Health HIV, *State of Aging with HIV: Third Annual National Survey, 2023*, <https://healthhiv.org/positivelyaging>.

³ Sean Cahill et al., “Strategies to Improve the Health of Older Adults Living with HIV,” *TargetHIV* (2016): 5, https://targethiv.org/sites/default/files/file-upload/resources/NCIHC_HIV%20and%20Aging_2016.pdf; Thurka Sangaramoorthy et al., “Older African Americans and the HIV Care Continuum: A Systematic Review of the Literature, 2003-2018,” *AIDS Behav.* 23, no. 4 (2019), <https://doi.org/10.1007/s10461-018-2354-4>.

⁴ “A person cannot be discriminated against in housing based on their membership in one or more protected classes. A protected class is a group of people protected by laws from discrimination based on a personal characteristic.” Fair Housing Center for Rights & Research, *Fair Housing for People with a Criminal Record: A Digital Toolkit*, 2022, <https://www.thehousingcenter.org/wp-content/uploads/2022/09/FAIR-HOUSING-FOR-PEOPLE-WITH-A-CRIMINAL-RECORD-A-DIGITAL-TOOLKIT.pdf>.

⁵ “Discrimination,” LII: Legal Information Institute, accessed June 13, 2024, <https://www.law.cornell.edu/wex/discrimination>.

Not every federal law protects every identity category from discrimination, however, and some laws, such as the Fair Housing Act, provide protection only within a specific area. There are also typically exceptions regarding when and to what extent these protections are applicable. For example, there are circumstances under which an employer is not required to provide reasonable accommodations to an employee under the Americans with Disabilities Act (ADA).

People Living and Aging with HIV (PLAHIV) face discrimination in multiple facets of their lives, though the ways it can appear are varied and target them in different ways. Many must contend with HIV stigma, or the fear or dislike of a Person Living with HIV (PLHIV) based on their serostatus.

One major category of stigma is the view of PLHIV as “vectors of disease” from whom people not living with HIV need to protect themselves. This can manifest in forms of discrimination such as the refusal to allow employees living with HIV to use shared employee spaces like a kitchen to “protect” the other workers. The imposition of such rules and limitations typically has little if any basis in the science of how HIV is transmitted. Another form of stigma appears as a mistrust or dislike of people who are thought to have acquired HIV after the early years of the epidemic, that is, after the methods of transmission became better understood. This kind of stigma casts

doubt on the decision-making skills of PLHIV and blames them for acquiring HIV, resulting in paternalistic policies where PLHIV need to be “protected” from themselves.

Many people living and aging with HIV face discrimination because of different aspects of their identities and lives, and those experiences have an impact on their ability to access services as they age.

Other aspects of the lives and identities of PLAHIV that can come under attack and that are protected by antidiscrimination laws are race, sex, and age, to name just a few.⁶ Not every component of one’s identity that causes differential or negative treatment is protected under an antidiscrimination law. And not all manifestations of bias, even in one of these categories, may be covered by antidiscrimination law. For example, in most cases it is perfectly acceptable to deny someone a job or housing based on their having a criminal record regardless of what kind of record it is. Demonstrating an explicit bias against people with a criminal record (as long as it is not being used as a proxy for discrimination against people based on race) is permitted under various federal antidiscrimination laws.

⁶ Federal antidiscrimination laws do not explicitly include gender identity or sexual orientation as specifically protected classes. However, the Obama and Biden administrations have argued that those identity categories are covered through the prohibitions against discriminating on the basis of sex. Sex Discrimination, 29 C.F.R. §1604 (2004), <https://www.eeoc.gov/laws/guidance/sex-discrimination#Q3>. This argument has its roots in the case of *Price Waterhouse v. Hopkins*, where the Supreme Court found that discrimination based on sex stereotyping (discrimination based in someone’s “failure” to conform to the stereotypical behaviors and dress associated with one’s sex) was discrimination on the basis of sex. *Price Waterhouse v. Hopkins*, 490 U.S. 228 (1989). The plaintiff in *Price Waterhouse* was denied a promotion due to being viewed as too aggressive or harsh for a woman and failing to dress femininely enough for the decision makers. *Price Waterhouse v. Hopkins*, 490 U.S. 228 (1989). Using this decision as the foundation of their legal strategy, transgender people began bringing lawsuits alleging discrimination based on sex due to sex stereotyping, some of which were successful and others of which failed, leading to a circuit split (different courts nationally coming to different legal conclusions). Katie Eyer, *Protecting Lesbian Gay Bisexual and Transgender (LGBT) Workers: Strategies for Bringing Employment Claims on Behalf of Members of the LGBT Community in the Absence of Clear Statutory Protections*, American Constitutional Law Society, July 2006, 6-7, <http://dx.doi.org/10.2139/ssrn.1441282>. After almost two decades of inconsistent decisions regarding whether or not discrimination on the basis of gender identity and/or sexual orientation constituted discrimination on the basis of sex, in 2020 the Supreme Court consolidated several cases and ruled that it in fact was; that an employee was discriminated against on the basis of sex if they suffered a negative employment action due to their sexual orientation or gender identity. *Bostock v. Clayton County*, 140 S. Ct. 1731 (2020). Although this is a decision to be celebrated, the fact that this protection comes through case law (ie due to the interpretation of a statute by the court) instead of through explicit amendments or new federal law means that it is vulnerable to recession through reinterpretation by a future Supreme Court, similarly to how the *Dobbs* decision overturned *Roe v. Wade*’s protection of the right to chose (i.e., to have an abortion).

Regardless of whether a form of discrimination or bias is covered by antidiscrimination laws, many PLAHIV face discrimination because of different aspects of their identities and lives, and those experiences have an impact on their ability to access services as they age. For example, nearly half of LGBTQ+ residents in long-term care facilities have been mistreated in ways ranging from verbal harassment to expulsion based on their real or perceived sexual orientation and/or gender identity.⁷ For many older LGBTQ+ people, this comes after a lifetime of similar mistreatment and discrimination, much of it either sanctioned by or directly caused by the state. As a result, they are more likely to have lower incomes and when faced with discrimination, lack the resources to pursue remedies.⁸ Also as a result, more than three-quarters of LGBTQ+ residents in nursing homes, assisted living facilities, and long-term care facilities are uncomfortable being open about their sexual orientation or gender identity with facility staff.⁹ This is despite the fact that in many states people cannot be discriminated against based on their gender presentation in areas of “public accommodation,” such as nursing homes, under the current interpretation of antidiscrimination laws.

It is important to note that antidiscrimination laws are almost entirely nonresponsive to the ways in which PLAHIV may be targeted due to their intersectional identities. The laws can only address the harms caused by differential treatment based on each characteristic separately. In 1989, law professor Kimberlé Crenshaw coined the term “intersectionality”

to describe Black women’s multilayered experiences of institutional oppression (manifested in part as discrimination). Since then the term has become a framework for understanding how a person’s identities (race, gender, sexuality, etc.) compound the totality of harm that individuals and communities experience each day.¹⁰ Crenshaw argued that to recognize the discrimination that a Black woman experiences requires one to recognize that such oppression cannot be fully understood by splitting her experiences into their component parts.¹¹ She is targeted not just due to her race (Black), or just due to her sex (female), which are both protected classes, but due to the mythology, stereotypes, prejudice, and stigma directed towards her identity as a whole (Black woman).

For example, although discrimination on the basis of race or sex is barred by the Federal Civil Rights Act of 1964, laws that permit the child welfare (or family regulation) system to intercede in people’s lives has allowed for the children of Black mothers with a substance use disorder to be removed at a much higher rate than the children of white mothers with a substance use disorder.¹² Because the Civil Rights Act, as commonly interpreted by the courts, does not take account of the intersectional discrimination experienced by Black women, it is unable to protect them. It is this inattention to intersectionality that renders the overarching framework of protections offered by antidiscrimination laws less effective.

⁷ *Dignity Denied Religious Exemptions and LGBTQ+ Elder Services*, Movement Advancement Project, December 2017, 1, <https://www.lgbtmap.org/dignity-denied-lgbt-older-adults>.

⁸ Denny Chan, *How Can Legal Services Better Meet the Needs of Low-Income LGBTQ+ Seniors?*, Justice in Aging, June 2016, 2, <https://justiceinaging.org/wp-content/uploads/2016/06/How-Can-Legal-Services-Better-Meet-the-Needs-of-Low-Income-LGBT-Seniors.pdf>.

⁹ Chan, *Legal Services*, 6.

¹⁰ Kimberlé Crenshaw, “Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics,” *University of Chicago Legal Forum* 1989, no. 1 (1989): 139-67, <https://chicagounbound.uchicago.edu/cgi/viewcontent.cgi?article=1052&context=uclf>.

¹¹ Jasmine E. Harris, “Reckoning with Race and Disability,” *Yale Law Journal* 130 (June 30, 2021): 926. “Crenshaw argued that our system of protected classifications artificially siloed a person’s identity such that one could be a woman or Black person but, at least categorically for antidiscrimination purposes, not both. Importantly, Crenshaw surfaced a central insight, that intersectional discrimination operated independent of its components such that the experience of subordination could not simply be captured by any one classification.”

¹² Janet M. Turan et al., “Challenges and Opportunities in Examining and Addressing Intersectional Stigma and Health,” *BMC Med* 17, no. 7 (2019). <https://doi.org/10.1186/s12916-018-1246-9>.

What Federal Protections Exist for People Living and Aging with HIV?

The federal laws outlined here are not all of the federal laws that protect PLAHIV from discrimination, but they represent some of the important ones.

THE AMERICANS WITH DISABILITIES ACT

One of the most robust sets of protections for people living with HIV comes from the Americans with Disabilities Act (ADA).¹³ Congress enacted the ADA in 1990 “to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities.”¹⁴ The protections of the ADA preempt, or take precedence over, any state law that is in conflict with them, as written, or as applied.¹⁵ Since the ADA’s passage in 1990, and through its subsequent updates and amendments, Congress has directed the courts to take an expansive and inclusive view of disability, defined as any “physical or mental impairment that substantially limits one or more major life activities” or with a history or perception of such impairment.¹⁶ HIV is a covered disability protected by the ADA, regardless of a person’s viral load or of the impact that living with HIV currently has on their

ability to navigate their day-to-day life.¹⁷ Courts have repeatedly rejected reliance on unfounded fears and stereotypes about HIV as a basis for singling out and negatively treating those living with HIV.¹⁸

The ADA consists of five sections, or titles, each of which covers a different subject area and has slightly different rules for exactly how extensively that area is covered and what the exceptions are. The titles are:

- I. Employment:** Prohibits discrimination by employers with 15 or more employees in the private sector, state and local governments, and labor unions. Covered employers must provide reasonable accommodations to employees with disabilities.
- II. Public Entities (and Public Transportation):** “[P]rohibits public entities, including state and local governments, from discriminating against ‘qualified individuals with disabilities’

¹³ The author is aware of the debates that exist regarding what groups of people want to be or should be considered disabled, including people living with HIV due to the stigma associated with the identification. For the purposes of this primer, the author is not making any assertions as to which side is “correct,” acknowledging the complex concerns on both sides responsive to the intersectional stigmas that PLHIV face. The main purpose of this primer is to try and make clear what protections exist for PLAHIV so they can utilize them as they wish, and currently an important vehicle for those protections is the ADA.

¹⁴ Equal Opportunity for Individuals with Disabilities, 42 U.S.C. § 12101(b)(1)(2008); Section 504 of the Rehabilitation Act prohibits discrimination on the basis of disability as well. However, the courts have traditionally analyzed claims under both statutes identically. Therefore this primer will only discuss the ADA. *Henrietta D. v. Bloomberg*, 331 F. 3d 261, 272 (2d Cir. 2003) (citing *Weixel v. Bd. of Educ.*, 287 F. 3d 138, 146 n. 6 (2d Cir.2002)); *Rodriguez v. City of New York*, 197 F. 3d 611, 618 (2d Cir. 1999)(“Because Section 504 of the Rehabilitation Act and the ADA impose identical requirements, we consider these claims in tandem.”).

¹⁵ *Hindel v. Husted*, 875 F. 3d 344, 349 (6th Cir. 2017)(“a state procedural requirement may not excuse a substantive ADA violation,” and “[r]equiring public entities to make changes to rules, policies, practices, or services is exactly what the ADA does”)(internal citations omitted).

¹⁶ Joshua Blecher-Cohen, Disability Law and HIV Criminalization, *Yale Law Journal* 130 (April 2021): 1579; 42 U.S.C. §. 12102(1).

¹⁷ Nondiscrimination on the Basis of Disability in State and Local Government Services, 28 C.F.R. §35.108(a)(1)(i), (b)(2), (c)(1)(ii)(2016), <https://www.ada.gov/law-and-regs/regulations/title-ii-2010-regulations/>. Living with HIV was first found to be a disability through case law in the landmark decision *Bragdon v. Abbott*. *Bragdon v. Abbott*, 524 U.S.624 (1998). It was later protected through the passage of the ADA Amendments Act of 2008, by which Congress explicitly rejected a focus on whether someone’s health status qualified as a disability but instead mandated that focus be placed on whether discrimination occurred. ADA Amendments Act of 2008, 42 USCA § 12101 et. seq. (2008). “ADA Amendments Act of 2008, Pub. L. No. 110-325, 110th Congress, Second Session,” CHLP, October 2008, <https://www.hivlawandpolicy.org/resources/ada-amendments-act-2008-pub-l-no-110-325-110th-congress-second-session>.

¹⁸ *Doe v. Deer Mountain Day Camp, Inc.*, 682 F.Supp.2d 324, 347-48 (S.D.N.Y. 2010).

by excluding them from services and activities due to their disability.”¹⁹

III. Public Accommodations: Any of 12 different kinds of businesses that are open to the public cannot discriminate on the basis of disability. Any alteration or new construction by one of these businesses must be ADA compliant.

IV. Telecommunications: Telecommunications companies must provide functionally equivalent services to disabled people.

V. Miscellaneous Provisions: Important miscellaneous provisions are

1. Individuals who assert their rights under the ADA cannot be retaliated against
2. A disabled person is not required to accept an accommodation²⁰

The titles that are most applicable to the issues that PLAHIV may face are Titles I–III.

The Americans with Disabilities Act Title I: Employment

Title I of the ADA applies to all public and private employers with 15 or more employees.²¹ Real or perceived HIV status qualifies as a protected disability under this title, and covered employers may not discriminate on this basis when hiring or firing employees, designating job assignments or promotions, or granting wages and benefits.²²

However, Title I leaves some individuals vulnerable even when they are employed or are seeking employment at these covered institutions. The ADA prohibits discrimination against individuals who can “perform the essential functions of the job, either with or without reasonable accommodation” unless they

pose a significant risk to the health or safety of themselves or others that cannot be eliminated by reasonable accommodations.²³ This risk assessment “must be based on medical or other objective evidence,” and even a good faith belief in the existence of such risk does not allow employers to discriminate in the absence of such evidence.²⁴ The Department of Justice (DOJ), the federal body charged with enforcing the ADA, has expanded on this definition, writing in 2020, “The determination that a person poses a direct threat to the health or safety of others may not be based on generalizations or stereotypes about the effects of a particular disability; it must be based on an individual assessment that considers the particular activity and the actual abilities and disabilities of the individual.”²⁵ Recent case law involving employers who made employment decisions based on the purported risk posed by employing a PLHIV shows that courts are unlikely to accept an argument that a PLHIV poses a risk to others if employed.²⁶

A range of activities and options is encompassed by the phrase “reasonable accommodation.” A reasonable accommodation can be a physical change to one’s workspace, a change in hours, a change in responsibilities, or even the ability to take time off under Family Medical Act Leave (FMLA) without a fixed return date.²⁷ But just because it is determined that an employee or a prospective employee can perform a job activity with the use of a reasonable accommodation does not automatically entitle the individual to one. “Once an employer determines that an accommodation is reasonable, it is required to provide it, *unless* the employer can demonstrate that the requested accommodation would impose an undue hardship on the operation of

¹⁹ “The Americans with Disabilities Act of 1990-ADA,” Olmstead Rights, n.d., accessed June 11, 2024, https://www.olmsteadrights.org/about-olmstead/item.6460-The_Americans_with_Disabilities_Act_of_1990_ADA.

²⁰ “Introduction to the Americans with Disabilities Act,” ADA.gov, accessed June 11, 2024, <https://www.ada.gov/topics/intro-to-ada/>.

²¹ 42 U.S.C. §. 12111.

²² 28 C.F.R. §35.108(a)(1)(i), (b)(2), (c)(1)(ii).

²³ 42 U.S.C. §. 12111.

²⁴ *Bragdon v. Abbott*, 524 U.S. 624 (1998).

²⁵ “Questions and Answers: The Americans with Disabilities Act and Persons with HIV/AIDS,” U.S. Department of Justice, last updated February 25, 2020, https://archive.ada.gov/hiv/ada_ga_hiv.htm (emphasis added).

²⁶ *EEOC v. St. Joseph’s/Candler Health Sys.*, 2022 U.S. Dist. LEXIS 37741 (S.D. Ga. 2022); *EEOC v. Maxim Healthcare Services Inc., d/b/a Maxim Staffing Solutions*, Civil Action No. 14-CV-338 (W.D.Pa. 2014).

²⁷ ADA, Rehabilitation Act, 29 CFR § 1630, 29 CFR § 1614 (2002), <https://www.eeoc.gov/laws/guidance/enforcement-guidance-reasonable-accommodation-and-undue-hardship-under-ada#undue>.

the business. If the requested accommodation would impose an undue hardship, the employer is not required to provide the accommodation. An undue hardship is an action that requires ‘significant difficulty or expense.’”²⁸ If it is found that providing an accommodation will cause an undue disruption to the business operations, such as cause coworkers to be overburdened in a way that they cannot complete their regularly assigned tasks, then even if the accommodation is reasonable the employer is not required to provide it.²⁹ In such a situation, the employer should seek to find another accommodation that would not cause undue hardship.³⁰

A person is not generally required to inform their employer about a medical condition or disability and is not necessarily required to reveal their HIV status even when requesting a reasonable accommodation on the basis of a covered disability.³¹ However, an employer can request the individual’s medical records to substantiate the disability.³² By law, managers and supervisors must keep a person’s medical information confidential. But legal protections and remedies around privacy and confidentiality do not apply to coworkers in the same way they do to supervisors and managers. A coworker does not have a duty of confidentiality to a PLHIV.

The Americans with Disabilities Act Title II: Public Entities

Title II of the ADA prohibits government entities from engaging in discriminatory practices either directly, by explicitly excluding or denying someone’s access to programs, or indirectly, by failing to prevent or ameliorate such discrimination.³³ Examples of covered programs and activities include attending public schools,

accessing public recreation facilities, and receiving healthcare and social services.³⁴ Title II reads:

Subject to the provisions of this subchapter, no [1] qualified individual with a [2] disability shall, [3] by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity.³⁵

The government’s responsibility to ensure that “qualified individuals with disabilities” have access to its programs goes beyond merely assuring them that it does not actively exclude anyone; it must make certain that its programs are accessible. A qualified individual is someone who “with or without reasonable modifications... meets the essential eligibility requirements for the receipt of services or the participation in programs or activities provided by a public entity.”³⁶ It is important to note that the U.S. Supreme Court in *Olmstead* found that, when appropriate, disabled people have the right to receive state-funded supports and services in the community rather than be forced to receive them only within an institutional setting; that to do otherwise is essentially segregating disabled people on the basis of their disability.³⁷

If a government agency or program claims that the discrimination (differential treatment) is justified in the case of a PLHIV, there is then an inquiry into whether the person is “otherwise qualified” to access the service.³⁸ This determination requires application of the test found in *School Board of Nassau County v. Arline*, where the U.S. Supreme Court directs the lower courts to examine the (1) nature of the risk, (2) duration of the risk, (3) severity of the

²⁸ “Questions and Answers,” U.S. DOJ.

²⁹ 29 CFR § 1630, 29 CFR § 1614.

³⁰ 29 CFR § 1630, 29 CFR § 1614.

³¹ “HIV/AIDS and Your Rights: A Fact Sheet,” SAGE, September 2011, <http://lgbtagingcenter.org/library/item/hiv-aids-and-your-rights-a-fact-sheet/>.

³² “HIV/AIDS and Your Rights: A Fact Sheet,” SAGE.

³³ 42 U.S.C. § 12132.

³⁴ “State and Local Governments,” ADA.Gov, accessed June 11, 2024, <https://www.ada.gov/topics/title-ii/>.

³⁵ 42 U.S.C. § 12132(numbers added).

³⁶ 28 C.F.R. § 35.139(b).

³⁷ “Olmstead v. LC: History and Current Status,” accessed June 13, 2024, <https://www.olmsteadrights.org/about-olmstead/>.

³⁸ Joshua Blecher-Cohen, “Disability Law,” 1580.

Tennessee: Using the ADA in Creative Ways

The “criminalization of HIV” refers to laws that make illegal conduct by a PLHIV who is aware that they have HIV. Such laws not only specifically target PLHIV, but they also include prosecution under the general criminal code, as well as sentencing or other enhancements (increased penalties) that are applied based on HIV status.¹

In January 2022, the Center for HIV Law and Policy (CHLP) filed complaints with the Department of Justice in both Tennessee and Ohio claiming that the state’s HIV criminalization laws violate the rights of PLHIV under the Americans with Disabilities Act (ADA).² This is the first time the ADA has been used to challenge criminal laws in the United States.

HIV Criminalization in Tennessee

In Tennessee, it is against the law to “engage in, or offer to engage in, [sex work] as a business, [serve] as an inmate in a house of prostitution or loiter in a public place for the purpose of being hired to engage in sexual activity.”³ Violating this statute is a misdemeanor.⁴ However, if a PLHIV engages in sex work, they face aggravated prostitution (AP) charges, which is a Class C felony and punishable by 3 to 15 years imprisonment and a

fine of up to \$10,000.⁵ Until July 2024, under Tennessee law, when a PLHIV was convicted of AP, they were considered a “violent sexual offender” and required to enlist on the sex offense registry for life.⁶ A study by the Williams Institute at UCLA School of Law showed that these laws were almost exclusively used to prosecute Black Tennesseans, who represented 90% of all those arrested, and that 57% of those forced to register were Black women.⁷

In January 2022, CHLP filed complaints with the Department of Justice in both Tennessee and Ohio claiming that the state’s HIV criminalization laws violate the rights of PLHIV under the ADA.

DOJ Response/Findings

On December 1, 2023, in response to CHLP’s complaint, the DOJ found that Tennessee, the Tennessee Bureau of Investigations (TBI), and the Shelby County District Attorney General’s Office (SCDAG) discriminated against people with disabilities.⁸ The DOJ determined that Tennessee’s AP statute is a “blanket

¹ HIV Criminalization in the United States, A Sourcebook on State and Federal HIV Criminal Law and Practice, s.v. “Introduction,” CHLP, accessed April 28, 2024, 1, <https://www.hivlawandpolicy.org/sites/default/files/HIV%20Criminalization%20in%20the%20U.S.%20A%20Sourcebook%20on%20State%20Fed%20HIV%20Criminal%20Law%20and%20Practice%20022722.pdf>.

² 42 U.S.C. § 12132. “Subject to the provisions of this subchapter, no [1] qualified individual with a [2] disability shall, [3] by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity.”

³ Tenn. Code Ann. § 39-13-512(6).

⁴ Tenn. Code Ann. § 39-13-512(6).

⁵ Tenn. Code Ann. § 40-35-111(b)(3).

⁶ Tenn. Code Ann. §§ 40-39-202(31), § 40-39-207(g)(2); “Tennessee Removes Aggravated Prostitution from Offenses Requiring Sex Offender Registration,” CHLP, 2024, <https://www.hivlawandpolicy.org/news/news-release-tennessee-removes-aggravated-prostitution-offenses-requiring-sex-offender>.

⁷ Nathan Cisneros et al., *Enforcement of HIV Criminalization in Tennessee* (Williams Institute, 2022), 2, <https://williamsinstitute.law.ucla.edu/publications/hiv-criminalization-tennessee/>.

⁸ Rebecca Bond to Jonathan Skrmetti, David Rausch, and Steven Mulroy, December 1, 2023, State of Tennessee and Tennessee Bureau of Investigations Letter of Findings, <https://www.justice.gov/opa/media/1326876/dl?inline>.

criminalization of people living with HIV, which is not grounded in current medical knowledge,” therefore violating Title II of the ADA.⁹ They also found that the AP statute facially discriminated against PLHIV by singling them out for increased penalties, meaning that the intent to discriminate is in the text of the law itself, and not how it is applied.”¹⁰

The DOJ notified state officials of their findings and were unable to reach an agreement with them to remedy the violations. In February 2024, the DOJ filed a complaint in federal court alleging the discriminatory treatment Tennessee and the TBI inflict upon PLHIV violated the ADA.¹¹ The DOJ’s requests for relief included: ceasing all enforcement of the aggravated prostitution statute, removal of individuals from the registry who were only listed due to the aggravated prostitution conviction, compensatory damages to be paid to people impacted by the law, and record expungement for PLHIV with aggravated prostitution convictions.¹²

Where We Are Now

The Shelby County District Attorney’s office entered into a settlement with the DOJ in May 2024, agreeing to cease prosecutions under the aggravated prostitution statute. The Shelby County DA’s office was never a party to the lawsuit so this settlement does not impact the ongoing litigation.¹³ However, a recent letter written by Shelby County DA Steve Mulroy suggests that PLHIV will continue to be targeted. In his letter, Mulroy states that the DA’s office “[has] NOT agreed

to stop prosecuting prostitution. The normal prostitution statute remains at our disposal. As does the separate statute making it a Class C Felony to knowingly expose another person to HIV including by sexual contact.”¹⁴ This language essentially mirrors the aggravated prostitution statute and would have the same effects at minimum. However, with the passage of Senate Bill 0181/ House Bill 1384 those convicted of AP no longer have to register for a sex offense.¹⁵

The ADA is an exciting way to challenge the criminalization of people living with HIV and potentially for other health-related concerns.

Although the situation in Tennessee is still developing, the steps taken thus far show that the ADA is an exciting way to challenge the criminalization of people living with HIV and potentially for other health-related concerns. While ADA complaints may vary in effectiveness depending upon the state, the acceptance of the argument raised in CHLP’s complaint can be used as leverage to challenge other laws, even outside the courtroom.

⁹ Bond to Skrmetti, Rausch, and Mulroy, *Letter of Findings*.

¹⁰ Bond to Skrmetti, Rausch, and Mulroy, *Letter of Findings*.

¹¹ Complaint, United States v. Tennessee, No. 2:24-cv-2101, 2024 WL 646156 (W.D. Tenn. Feb. 15, 2024), https://www.justice.gov/d9/2024-02/complaint-u.s._v._state_of_tennessee_and_tennessee_bureau_of_investigation.pdf.

¹² Complaint, U.S. v. Tennessee.

¹³ Settlement Agreement, United States v. Tennessee, No. 2:24-cv-2101, 2024 WL 646156 (W.D. Tenn. Feb. 15, 2024).

¹⁴ Brent Taylor (@SenBrentTaylor), “LETTER ALERT Senator Taylor pens letter to A.G. Skrmetti regarding D.A.

Mulroy’s refusal to prosecute aggravated prostitution,” X, June 10, 2024, 9:28am, <https://x.com/SenBrentTaylor/status/1800158153666928753>.

¹⁵ “Tennessee Removes,” CHLP.

risk, and (4) probability of transmission.³⁹ Essentially, the ADA instructs officials to do an assessment to determine if someone with a communicable disease is actually a direct threat and if such a threat could be ameliorated through reasonable modifications to policies, practices, or procedures.⁴⁰

Laws that discriminate against PLHIV, intentionally or not, violate the ADA, and state enforcement of such laws can make the state government subject to DOJ prosecution.

The Department of Justice, which is responsible for prosecuting violations of the ADA, has made it clear that all activities, services, and programs of public entities are covered, including activities of state legislatures and courts, town meetings, police and fire departments, motor vehicle licensing, and employment.⁴¹ This means that laws that discriminate against PLHIV, intentionally or not, violate the ADA and that state enforcement of such laws can make the state government subject to DOJ prosecution. Recently, the DOJ responded to a complaint from the Center for HIV Law and Policy (CHLP) alleging that Tennessee laws criminalizing PLHIV were a violation of the ADA. The DOJ later filed suit against Tennessee's governor over the state's prosecution of PLHIV for aggravated prostitution. Therefore the ADA's prohibition against discrimination includes criminal as well as civil laws.

The Americans with Disabilities Act Title III: Public Accommodations

Title III of the ADA protects people with disabilities from discrimination based on their

disability with regard to their full and equal enjoyment of the goods, services, or facilities of any place of public accommodation. "A public accommodation is a private entity that owns, operates, or leases to a place of public accommodation. Places of public accommodation include a wide range of entities, such as restaurants, hotels, theaters, doctor's offices, dentist's offices, hospitals, retail stores, health clubs, museums, libraries, private schools, and day care centers."⁴²

Public accommodations such as nursing homes are expressly covered in the Title III regulation as social service center establishments. Other residential facilities, such as congregate care facilities, retirement communities, and independent living centers, are also covered by Title III if they provide significant social services such that they can be considered social service center establishments. The ADA Technical Assistance Manual further provides that social services in the context of the ADA include medical care, assistance with daily living activities, provision of meals, transportation, counseling, and organized recreational activities.⁴³ Of note, none of these services automatically trigger the ADA. Instead, the determination as to whether a private entity constitutes a social service center depends on the degree and nature of the services.

If a facility meets the criteria of a social services center, the facility must ensure that people living with disabilities are treated equally and that they have equal opportunity to benefit from safe, inclusive communities. Obviously, intentionally discriminatory activities such as segregating people living with HIV from other residents or clientele would not be permitted.⁴⁴ Entities must make reasonable modifications to policies, practices, and procedures as necessary to provide for equal treatment. Additionally,

³⁹ School Board of Nassau County v. Arline, 481 U.S. 1024, 1024 (1987).

⁴⁰ 28 C.F.R. § 35.139(b).

⁴¹ 28 C.F.R. § 35.190.

⁴² "Questions and Answers," U.S. DOJ.

⁴³ "ADA Title III Technical Assistance Manual," U.S. Department of Justice, last updated November 1, 1993, <https://www.ada.gov/resources/title-iii-manual/>.

⁴⁴ Kevin Barry et al., "Symposium: Contemporary Issues in Disability Rights Law, The Future of Disability Rights Protections for Transgender People," *Touro Law Review* 35 (2019): 28.

entities must also take appropriate steps to communicate effectively with people with disabilities. This may require that the facility provide auxiliary aids or assistance that would allow a PLAHIV to access their services, unless doing so would present an undue burden (i.e., significant difficulty or expense) to the facility.⁴⁵

THE OLDER AMERICANS ACT

The Older Americans Act (OAA) was first passed in 1965 as part of President Lyndon Johnson’s Great Society initiative to create a social service safety net for older Americans.⁴⁶ Over the decades since its initial passing it has been reauthorized and updated many times in an effort to improve its services and supports to allow people to live at home as they age.⁴⁷ It is mostly administered by the Administration for Community Living (ACL), the federal body responsible under Title III of the OAA for distributing funds to the states, which then distribute them to Area Agencies on Aging (AAAs).⁴⁸ The services provided and/or funded by the AAAs range from support for in-home resources and care, to support of various nutrition programs.⁴⁹ In February 2024, the ACL released the final rule of its latest rule-making process for the OAA (which is due to be reauthorized in 2024), and it contains several provisions that are of note for PLAHIV.⁵⁰

One portion of the rule to highlight is § 1321.3, in which LGBTQ+ people and PLHIV were

specifically mentioned as two groups that have the “greatest social need.”⁵¹ Services funded through Title III of the OAA are supposed to prioritize aiding aging people, and their caregivers, identified as having the greatest social need.⁵² This “[a]ffects all levels of Older Americans Act policy, funding, planning, and service delivery.”⁵³ This provision should translate into the needs of LGBTQ+ people and PLAHIV being explicitly incorporated into the State Plans on Aging, or blueprints for state services, expanding resources for and support to PLAHIV.⁵⁴ The inclusion will also make State Plans nationwide more consistent with the supports that they provide, instead of leaving prioritization decisions regarding PLAHIV entirely up to the states themselves, many of which do not have a good track record when it comes to caring for PLHIV.

A provision in the recent rule that does not go far enough is in the definition of family caregiver. Again, being included in Title III is how one gets money through the OAA. Although the rule adopted an expanded definition of caregiver, it failed to make explicit that chosen family should be included. If a category is not explicitly included then it could be excluded based on the interpretation of the rule by program administrators at the state and local levels. Adding chosen family to the rule would have made sure that PLAHIV could get funding for their chosen family to assist them. It will be

⁴⁵ “Questions and Answers,” U.S. DOJ.

⁴⁶ “Older Americans Act,” Administration for Community Living, last updated October 31, 2023, <https://acl.gov/about-acl/authorizing-statutes/older-americans-act#:~:text=Older%20Americans%20Act%20signed%20into,of%20State%20Units%20on%20Aging>.

⁴⁷ Emma Bessire, “Demystifying the Older Americans Act for People Living with HIV” (PowerPoint presentation, SAGE Webinar Series, May 2, 2024), <https://www.sageusa.org/resource-posts/demystifying-the-older-americans-act-for-older-people-living-with-hiv/>.

⁴⁸ Older Americans Act: Grants to State and Community Programs on Aging, 45 C.F.R. § 1321 (2024), <https://public-inspection.federalregister.gov/2024-01913.pdf>.

⁴⁹ Bessire, “Demystifying.”

⁵⁰ After Congress passes a law, the executive body in charge of enforcing it designs rules that explain how they interpret the law for enforcement. For example, the ACL, the executive body who administers the OAA, created the rule that sets out how it interprets the OAA and how it will enforce it, clarifying concepts as needed. The distinction between a statute and the rules is important because the provisions discussed in the next paragraph are in the rule, not the statute. It is entirely possible that, if there is a shifting of power at election time and new members of the ACL are appointed by a different president, these members would interpret the OAA differently. Being in the rule makes these provisions much more subject to political will and easier to change.

⁵¹ 45 C.F.R. § 1321.

⁵² 45 C.F.R. § 1321.

⁵³ Andrea Callow, “The Older Americans Act & Older Adults Living With HIV” (PowerPoint presentation, SAGE Webinar Series, May 2, 2024), <https://www.sageusa.org/resource-posts/demystifying-the-older-americans-act-for-older-people-living-with-hiv/>.

⁵⁴ Callow, “The Older Americans Act.”

important in the upcoming 2024 reauthorization of the OAA for advocates to push to get this explicit language added.

THE AGE DISCRIMINATION IN EMPLOYMENT ACT OF 1967

The Age Discrimination in Employment Act (ADEA) makes it unlawful for employers to discriminate against any individual employee over the age of 40.⁵⁵ This prohibition extends to all parts of employment: recruitment, hiring, firing, promotion, layoff, compensation, benefits, job assignments, and training.⁵⁶ “In passing the ADEA, Congress recognized that age discrimination was caused primarily by unfounded assumptions that age impacted ability. To prevent and stop such arbitrary discrimination, the ADEA requires employers to consider individual ability, rather than assumptions about age, in making an employment decision.”⁵⁷

People living with HIV are more likely to be, or to have been, lower income and may not have been able to set aside sufficient funds for their retirement.

This law has relevance for PLAHIV, indeed, for anyone aging in the United States today, because of the changing demographics of the workforce. No longer do people, primarily men, work at one job in one sector for their entire career. Instead, on average people change jobs five to six times during their working lives. In general, the workforce is aging, although perceptions of the competence of older people is not shifting. Finally, because they often do not have sufficient funds, many older Americans are

forced to come out of retirement and reengage with the workforce to make ends meet. PLAHIV are more likely to be, or to have been, lower income and may not have been able to set aside sufficient funds for their retirement. People who are working longer or are coming out of retirement often find themselves in competition with younger employees, and the ADEA is intended to protect older Americans from any negative consequences of that reality.

THE CIVIL RIGHTS ACT OF 1964

The Civil Rights Act of 1964 prohibits discrimination on the basis of race, color, religion, sex, or national origin. The vast amount of case law and extensive history of activism both prior to and after its passage is beyond the scope of this primer, but one recent court decision interpreting the law’s provisions is worth highlighting. In the 2020 case of *Bostock v. Clayton County* the plaintiff, a gay man, sued Clayton County, Georgia, claiming that he had been fired from his county job for being gay.⁵⁸ He claimed that under Title VII of the Civil Rights Act, protections against discrimination on the basis of sex, the firing was unlawful. The U.S. Supreme Court agreed, ruling that firing him for being gay amounted to discrimination under Title VII, that he had been fired because of his sex. Thus, the Civil Rights Act of 1964 could be used to combat discrimination that LGBTQ+ PLAHIV face in employment if it is due to their LGBTQ+ identity.⁵⁹ Also, to this day, the stereotype remains that HIV is a “gay man’s disease.” *Bostock* could provide protections to someone who is fired because their employer found out they were living with HIV and believed them to be gay, regardless of their sexual orientation. Furthermore, the decision in *Bostock* opened the door for courts to make a more intersectional analysis in cases where

⁵⁵ “Editor’s Note: The Age Discrimination in Employment Act of 1967,” U.S. EEOC, accessed June 14, 2024, <https://www.eeoc.gov/statutes/age-discrimination-employment-act-1967>.

⁵⁶ “Editor’s Note,” U.S. EEOC.

⁵⁷ Victoria Lipnic, *The State of Age Discrimination and Older Workers in the U.S. 50 Years After the Age Discrimination in Employment Act (ADEA)*, June 2018, <https://www.eeoc.gov/reports/state-age-discrimination-and-older-workers-us-50-years-after-age-discrimination-employment>.

⁵⁸ *Bostock v. Clayton County*, 140 S. Ct. 1731 (2020).

⁵⁹ *Bostock*, 140 S. Ct. 1731. The *Bostock* decision encompassed three consolidated cases. The plaintiff in one was a trans woman who was fired due to her gender identity. Thus the *Bostock* decision applies to transgender people as well.

the person fired is a member of a protected class.⁶⁰ This lessens the ability of employers to use “valid” reasons as pretextual cause for employment decisions that are ultimately based on one’s protected identity(s).

THE FAIR HOUSING ACT

The impact of the Fair Housing Act (FHA) is limited to the arena of housing, but as affordable housing is a dire need of PLAHIV, the law is a vital protection. The Fair Housing Act (FHA) was passed as part of the Civil Rights Act of 1968.⁶¹ The purpose of the FHA was “to provide, within constitutional limitations, for fair housing throughout the United States,” encompassing all publicly or privately owned or rented housing.⁶² It applies to *all* “housing related transactions” which includes: renting, buying, selling, applying for a loan, appraisal services, and homeowners insurance.⁶³ It therefore, “[P]rohibits discrimination by direct providers of housing, such as landlords and real estate companies as well as other entities, such as municipalities, banks or other lending institutions and homeowners insurance companies.”⁶⁴ Discrimination is broadly defined by the FHA to include all of the kinds of conduct it was

passed to combat, such as trying to steer a member of a protected class away from a particular neighborhood.⁶⁵ Similarly, the FHA was designed to reach all discriminatory effects (i.e., “when there is a neutral practice or policy that disproportionately impacts a protected class) regardless of whether or not those effects were intended.”⁶⁶ The FHA was therefore designed to try and reach as much discriminatory conduct towards protected classes as possible.

As of the 1988 amendments, there are seven “protected classes” under the Fair Housing Act: race, color, national origin, religion, sex, disability, families with children.⁶⁷ The Act defines disability as “(1) a physical or mental impairment which substantially limits one or more of such person’s major life activities, (2) a record of having such an impairment, or (3) being regarded as having such an impairment,” which includes HIV.⁶⁸ The Department of Justice, one of the enforcers of the FHA, targets two areas in particular for disabled people: (1) the use of zoning provisions to prohibit communal living arrangements or congregate housing (which can include housing meant to include PLHIV); and (2) making sure that new construction of multifamily units

⁶⁰ The *Bostock* decision directed the lower courts to expand their interpretation of “but for” causation. The “but for” cause is the actual cause of an event, asking the question “but for the existence of ‘x’ would ‘y’ have occurred?,” LLI, “but-for test,” Cornell Law School, accessed July 15, 2024, https://www.law.cornell.edu/wex/but-for_test#:~:text=The%20but%2Dfor%20test%20is,in%20combination%20with%20proximate%20cause. The *Bostock* decision codified the fact that “[1]But for” cause does not mean sole cause [;][2]Events can have multiple “but for” causes [;][3]A protected trait does not need to be the primary reason to be the “but for” reason.” Sandra Sperino, “Comcast and Bostock Offer Clarity on Causation Standard,” *Human Rights Magazine*, January 11, 2021, https://www.americanbar.org/groups/crsj/publications/human_rights_magazine_home/civil-rights-reimagining-policing/comcast-and-bostock-offer-clarity-on-causation-standard/#:~:text=In%20Bostock%2C%20the%20Court%20held,discriminating%20%2%80%9Cbecause%20of%20%20sex. By clarifying that the “but for” cause does not need to be either the sole or the primary reason, it mitigates the ability to name one or more “legitimate” reasons to be the justification for a negative employment action limiting an employer’s ability to paper over the truth.

⁶¹ Judith Browne-Dianis and Anita Sinha, “Exiling the Poor: The Clash of Redevelopment and Fair Housing in Post-Katrina New Orleans,” *Howard Law Journal* 51 (2008): 493.

⁶² Civil Rights Act, 42 U.S.C. § 3601 et seq. (1968).

⁶³ Fair Housing Center, *Fair Housing*, 3.

⁶⁴ Civil Rights Division, “The Fair Housing Act,” Department of Justice, accessed June 20, 2024, <https://www.justice.gov/crt/fair-housing-act-1>.

⁶⁵ “An Introduction to Fair Housing” (PowerPoint presentation, National Housing Law Project), <https://www.nhlp.org/wp-content/uploads/2017/09/Fair-Housing-Intro-PPT.pdf>.

⁶⁶ “An Introduction to Fair Housing,” NHLPP; DOJ and HUD, 2016, *Joint Statement of Housing and Urban Development and the Department of Justice: State and Local Land Use Laws and Practices and the Application of the Fair Housing Act*, November 10, 2016, <https://www.justice.gov/opa/file/912366/dl>.

⁶⁷ Discrimination in the sale or rental of housing and other prohibited practices, 42 U.S.C. § 3604 (1988); Robert G. Schwemm, “Source of Income Discrimination and the Fair Housing Act,” *Case Western Res. J.* 70 (Spring 2020): 577. Currently, via executive order, the definition of “sex” under the FHA encompasses sexual orientation and gender identity. Exec. Order No. 13988, 86 Fed. Reg. 7023 (January 20, 2021).

⁶⁸ 42 U.S.C. § 3602(h); Civil Rights Division, “The Fair Housing Act.”

meets accessibility requirements under the FHA.⁶⁹ HUD is charged with enforcing other provisions under the FHA. Under the FHA, housing providers are required to provide/permit reasonable accommodations (a “change, exception, or adjustment to a rule, policy, practice, or service”) and reasonable modifications (“a structural change made to existing premises, occupied or to be occupied by a person with a disability”) in order for a disabled person to have full use and enjoyment of the premises.⁷⁰ Private housing providers are not required to pay for such modifications.⁷¹

SECTION 1557 OF THE AFFORDABLE CARE ACT

The purpose of Section 1557 of the Affordable Care Act (ACA, aka “Obamacare”) is to improve access to healthcare, primarily by reducing barriers and through strengthening protections against discrimination on the basis of race, color, national origin, sex, age, or disability.⁷²

The programs covered by this law are any health plan or activity receiving federal money or any program administered by the federal government.⁷³ Exactly what this means, and who is included as a protected class, has expanded and contracted since Section 1557’s passage through the enactment of rules by the Obama, Trump, and Biden administrations regarding interpretation and enforcement, and through litigation that has challenged every version of the rules.⁷⁴ Important interpretations and expansions under the Biden rule are:

- Healthcare providers and suppliers who receive Medicare Part B payments

are subject to the antidiscrimination requirements of Section 1557.

- Covered providers must make it known to people with limited English proficiency that no-cost language assistance programs are available to aid them.
- Interprets the definition of “sex” in Section 1557 to include protecting people from discrimination on the basis of gender identity and sexual orientation.
- Clarifies that covered insurance plans cannot discriminate against any protected class, including not only in who they cover but also in how they structure their benefits, make coverage decisions, and impose limits on coverage.
- Provides protections on the basis of sex characteristics (including intersex traits), and pregnancy-related conditions, including termination.
- Forbids benefit designs that do not provide health insurance coverage for qualified individuals with disabilities (which includes PLHIV) in integrated (“Olmstead”) settings.⁷⁵

What this means, practically speaking, is that covered providers (currently including covered insurance providers) cannot treat PLAHIV differently from other older Americans on the basis of their HIV status, regardless of the cost of their care. Since HIV is a covered disability under the ADA, as amended in 2008, protections from discrimination based on HIV status are integrated directly into Section 1557 through its explicit incorporation of the definition of disability used by the ADA.⁷⁶ But

⁶⁹ Civil Rights Division, “The Fair Housing Act.”

⁷⁰ “Reasonable Accommodations and Modifications,” HUD, accessed June 21, 2024, https://www.hud.gov/program_offices/fair_housing_equal_opp/reasonable_accommodations_and_modifications.

⁷¹ “Reasonable,” HUD.

⁷² “Section 1557 Final Rule: Frequently Asked Questions,” HHS, last updated May 20, 2024, <https://www.hhs.gov/civil-rights/for-individuals/section-1557/faqs/index.html>.

⁷³ Nondiscrimination, 42 U.S. Code § 18116 (March 23, 2010).

⁷⁴ Lindsey Dawson et al., “The Biden Administration’s Final Rule on Section 1557 Non-Discrimination Regulations under the ACA,” KFF, May 15, 2024, <https://www.kff.org/affordable-care-act/issue-brief/the-biden-administrations-final-rule-on-section-1557-non-discrimination-regulations-under-the-aca/>.

⁷⁵ 45 C.F.R. § 92.101 (2024); 45 C.F.R. § 92.201 (2024); 45 C.F.R. § 92.206 (2024); 45 C.F.R. § 92.207 (2024); Health and Human Services Agency, “HHS Issues New Rule to Strengthen Nondiscrimination Protections and Advance Civil Rights in Health Care,” news release, April 26, 2024, <https://www.hhs.gov/about/news/2024/04/26/hhs-issues-new-rule-strengthen-nondiscrimination-protections-advance-civil-rights-health-care.html>; Dawson, “The Biden Administration.”

⁷⁶ 42 U.S. Code § 18116.

the category of “covered provider,” or who is subject to the nondiscrimination clauses of Section 1557, depends upon the interpretation by different presidential administrations, and therefore may expand and contract with each election year. Furthermore, due to the recent *Loper Bright* decision the interpretations of statutory language by administrative agencies is potentially even more vulnerable to politics as the decision empowers judges to reject the agency interpretations in certain circumstances.⁷⁷ Thus a conservative judge can halt enforcement of challenged provisions, as was done in the July 3, 2024 injunction issued in the *Texas v. Becerra* case which enjoined enforcement of the inclusive definition of sex discussed above.⁷⁸ So the impact of that protection on one’s actual life and care is subject to change.

A LOOMING THREAT: THE RELIGIOUS FREEDOM RESTORATION ACT

Until this point, this section has highlighted many, but not all, federal laws that provide protections for PLAHIV. The Religious Freedom Restoration Act (RFRA) as it has been interpreted and applied by the courts, including the Supreme Court, lurks on the horizon as a threat to many of these protections. RFRA was passed with overwhelming support by both Democrats and Republicans in 1993 in direct response to the Supreme Court’s decision in *Oregon v. Smith*, a case where two Native Americans sued after being fired for smoking peyote during a religious ceremony.⁷⁹ In the *Smith* case, the Court found against the Native American plaintiffs, holding that even though the challenged law caused them to lose their jobs due to their religious practice, the law did not violate the First Amendment Free Exercise Clause (commonly

referred to as “freedom of religion”) because it did not *target* Native Americans specifically.⁸⁰

However, even though RFRA was passed in an effort to shield Americans’ sincerely held religious beliefs and practices from even inadvertent infringement by the government, it is currently being wielded by the religious Right to challenge laws with which they do not agree. A major target for those attacks has been the Affordable Care Act, where the contraceptive mandate (*Hobby Lobby* and *Little Sisters*) and preventative care, including access to PrEP (*Braidwood*) have been challenged.⁸¹ Challenges have also been raised to state laws that protect against discrimination in public accommodations for lesbian and gay people (*Masterpiece Cakeshop*) with RFRA as the basis for that challenge.⁸² What is particularly troubling about these attacks is that even if the Supreme Court does address the RFRA claim, justices have indicated strongly that they believe that RFRA should give people the right to discriminate on the basis of religion, no matter how slight any so-called harm faced by the religious plaintiffs would be.

An expansion of the religious Right’s ability to discriminate on religious grounds would potentially put many services utilized by PLAHIV at risk. As of 2011, 14% of all hospitals in the U.S. were religiously affiliated — meaning 17% of all hospital beds nationally could be impacted by licenses to discriminate under RFRA.⁸³ Every decision that expands “protections” for right-wing religious beliefs is a decision that could allow doctors to refuse care to LGBTQ+ people. And U.S. Supreme Court Justice Brett Kavanaugh has indicated that he believes that RFRA is a “super statute,” one that could essentially bypass all the statutory protections against discrimination.⁸⁴

⁷⁷ *Loper Bright Enters. v. Raimondo*, 144 S. Ct. 2244 (2024).

⁷⁸ *Texas v. Becerra*, No. 6:24-cv-211-JDK, 2024 U.S. Dist. LEXIS 117573 (E.D. Tex. July 3, 2024).

⁷⁹ Employment Division, Department of Human Resources of Oregon v. Smith, 494 U.S. 872 (1989).

⁸⁰ When a law targets a group specifically that is known as “facial discrimination.” Facial discrimination is much easier to show than “as applied” discrimination.

⁸¹ *Burwell v. Hobby Lobby Stores, Inc.*, 573 U.S. 682 (2014); *Little Sisters of the Poor Saints Peter & Paul Home v. Pennsylvania*, 140 S. Ct. 2367 (2020); *Braidwood Management, Inc. v. Becerra*, 666 F.Supp.3d 613 (N.D.Texas 2023).

⁸² *Masterpiece Cakeshop, Ltd. v. Colorado Civil Rights Commission*, 584 U.S. 617 (2018).

⁸³ *Dignity Denied: Religious Exemptions and LGBT Elder Services*, Movement Advancement Project, December 2017, 1, <https://www.lgbtmap.org/policy-and-issue-analysis/dignity-denied-lgbt-older-adults>.

⁸⁴ *Masterpiece Cakeshop*, 584 U.S. 617 (2018).

Montana Legislates a Right to Discriminate

In October 2023, Montana became the latest state to expand the “right to consciously object” from traditionally controversial medical procedures such as abortion to encompass any and all healthcare services. The Implement Medical Ethics and Diversity Act, creates the ability for medical practitioners, healthcare institutions, and healthcare payers¹ to refuse to provide or cover any medical services because of “ethical, moral, or religious beliefs or principles.”² Notably, the act leaves the victims of these “acts of conscience” no option for legal recourse, such as a medical malpractice lawsuit.³ Particularly at risk for denial of services are transgender patients, People Living with HIV (PLHIV), and people seeking abortion care.

This bill is another example of the coordinated national attack against peoples’ bodily autonomy and self-determination under the guise of “religious freedom.”

This bill is another example of the coordinated national attack against peoples’ bodily autonomy and self-determination under the guise of “religious freedom.” Bill sponsor Republican House Judiciary Chair Amy Rieger claims that the impetus for the bill is to retain medical workers who would stop practicing or otherwise leave Montana because they do not want to prescribe marijuana, perform abortions, or provide gender-affirming care.⁴ According to supporters, the law is meant to fill gaps left by federal law(s) so Montana medical professionals are empowered to practice medicine guided by their conscience.⁵ Amy Regier is sister to Matt Regier, Speaker of the Montana State House, and the daughter of Keith Regier, the Senate Judiciary chair.⁶ The Regiers have a history of engaging in anti-trans and anti-abortion work, which includes the creation of a political action committee called Doctors for a Healthy Montana.⁷ Amy Regier brought the bill, HB 303, to the House floor with the assistance of the Alliance Defending Freedom and the Religious Freedom Institute.

¹ The act defines “health care payer” as “an employer, health plan, health maintenance organization, insurance company, management services organization, or another entity that pays for or arranges for payment for a health care service, in whole or in part. Mont. Code Ann. § 50-4-1101(4) (West 2023).

² Mont. Code Ann. § 50-4-1101(1)(a) (West 2023).

³ Mont. Code Ann. § 50-4-1102(2) (West 2023); Carly Graf, “Montana’s Medical Conscience Objection Law Starts in October,” *Governing*, August 8, 2023, <https://www.governing.com/health/montanas-medical-conscience-objection-law-starts-in-october>.

⁴ Shaylee Ragar, “House Passes Bill Letting Health Workers Opt out of Cases on Moral Grounds,” *Montana Public Radio*, February 8, 2023, <https://www.mtpr.org/montana-news/2023-02-08/house-passes-bill-letting-health-workers-opt-out-of-cases-on-moral-grounds>.

⁵ Graf, “Montana’s Medical Conscience Objection Law.”

⁶ Matt Regier recently made news for leading the move to censure and bar Zooley Zephyr, the Montana legislature’s only transgender representative, for speaking out against a measure banning hormone treatments and surgical care for transgender minors. Despite Representative Zephyr’s work, the bill, SB 99: “Provide for a youth health protection” became law but was temporarily blocked in September of 2023 by a Montana state district judge. Shaylee Ragar and Acacia Squires, “Montana House Votes to Formally Punish Transgender Lawmaker, Rep. Zooley Zephyr,” *NPR*, April 26, 2023, <https://www.npr.org/2023/04/26/1172158461/montana-gop-transgender-zooley-zephyr-punishment-banned-speaking-lgbtq>. In the 2011 Session, Keith Regier compared pregnant women to cows, stating that the value of cattle increases when pregnant. Caleb Soptelean, “Women Object to Kalispell Legislator’s Words,” *Daily Inter Lake*, March 16, 2011, <https://dailyinterlake.com/news/2011/mar/16/women-object-to-kalispell-legislators-words-6/>.

⁷ Mike Baker and Jacey Fortin, “One Family Has Spearheaded Montana’s Unflinching Conservatism,” *New York Times*, May 4, 2023, Late edition.

The act grants the ability to whole institutions and/or corporations to raise a conscience objection to providing medical care, justified by that entity's governing documents (ethical, moral, or religious guidelines or directives, mission statements...), and to do so with no fear of liability.⁸ Intermountain Health is just one of the Catholic-run healthcare systems in Montana that abides by "Ethical and Religious Directives for Catholic Health Care Services" (ERDs), directly from the U.S. Conference of Bishops.⁹ Intermountain employs a Chief Catholic Mission Officer (CCMO) who advises healthcare leaders on upholding the ERDs. The current CCMO does not have an educational or work background in any medical field (beyond an M.A. in "Healthcare Ethics").¹⁰

Intermountain includes major hospitals like St. James Hospital, the largest acute care hospital in southwest Montana, alongside physician clinics, home health, hospice, and safety net services. Under the act, patients seeking healthcare services not aligned with the ERDs could be turned away without being aware of the possibility beforehand.

Similarly, Compassus is a nationwide Catholic Health Care-sponsored service that provides home health and hospice services in Montana. The act leaves those who seek care with Compassus at risk of becoming victims to a conscience objection without access to any meaningful recourse.¹¹ "Conscience objectors" have little to do in order to

properly justify their failure to render care; a mere writing that refers to the grounds of "conscience" satisfies the requirement.¹²

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This law creates a dire scenario for patients, especially PLAHIV, who could be refused care because of their diagnoses, perceived gender presentation, or perceived sexual orientation. Additionally, the act is broad enough to include any possible interaction PLAHIV could have with the healthcare system. They face denial at each step: making an appointment with their doctor, nurse, or counselor; receiving and filling a prescription; and receiving coverage for the prescription with insurance. Each interaction brings a risk of a conscientious objector exercising their right to refuse.

⁸ Mont. Code Ann. § 50-4-1101(1)(b) (West 2023).

⁹ "Our Catholic Health Ministry," Intermountain Healthcare, 2023, <https://intermountainhealthcare.org/about/catholic-care>. Many of these clinics have generic names, such as Intermountain, that obfuscate their affiliation with Catholicism.

¹⁰ "Our Catholic Health Ministry," Intermountain Healthcare.

¹¹ Mont. Code Ann. § 50-4-1101(6)(a-b) (West 2023).

¹² Mont. Code Ann. § 50-4-1103(2) (West 2023): "A health care institution may require the exercise of conscience as a basis for not participating in a health care service to be made in writing and signed by the medical practitioner objecting. A writing made under this subsection may refer only generally to the grounds of 'conscience.'"

How Can People Living and Aging with HIV Access Federal Protections?

There are several federal bodies responsible for handling complaints of violations under these statutes. Typically, a person can file a complaint that the body then investigates. How they can assist depends upon the body and the power it is given under the statute.

Equal Employment Opportunity Commission (EEOC)

The EEOC enforces federal laws prohibiting employment discrimination including under Title I of the ADA, the ADEA, and Title VII of the Civil Rights Act. To file a complaint, someone needs to first go to its portal (<https://publicportal.eeoc.gov/Portal/Login.aspx>) or call 1-800-669-4000 to file an inquiry. The inquiry will then be evaluated to see whether there is a valid claim. If it potentially is, the person can decide to file a complaint, called a Charge of Discrimination, which must be filed either 180 days or 300 days from when the discrimination occurred depending on the state.⁸⁵ If someone files, the EEOC is required to let their employer know within 10 business days, but the employer is forbidden to take any form of retaliation. After that, the person may be given the option to mediate with their employer, or the EEOC will start its investigation into the complaint. If it finds discrimination, it will issue a Letter of Determination to the individual and their employer and attempt to help both parties to resolve the situation. If no resolution is reached, the EEOC may file a suit in the case, or the person is given the option to retain counsel to sue.⁸⁶

The Department of Justice (DOJ)

The DOJ is responsible for enforcement of the ADA Title II (State and Local Governments) and Title III (Public Accommodations) and for portions of the Fair Housing Act, among many other federal laws and statutes. “The Department of Justice is authorized to investigate complaints and to bring lawsuits in

cases of general public importance, or where there is a pattern or practice of discrimination. The Department may seek injunctive relief (such as having the public accommodation correct its discriminatory practices), monetary damages, and civil penalties. Due to resource limitations, the Department is unable to investigate every complaint that it receives.”⁸⁷ If someone has faced discrimination under one of these categories, such as by a public or private healthcare provider, on the basis of living with HIV, they can file a report at <https://civilrights.justice.gov/> or mail:

U.S. Department of Justice
Civil Rights Division
Disability Rights Section
950 Pennsylvania Ave., NW
Washington, D.C.20530

After a person files a complaint, the DOJ may investigate if it is the kind of complaint that it handles. There are several potential outcomes of an investigation, one of which is that the DOJ may issue a Findings letter detailing discrimination and making suggestions as to what must be done to correct the problem. It will then attempt to negotiate an agreement. Please note, the person who filed the complaint is not represented by the DOJ or a “party”; therefore, they may not be privy to what is discussed in these negotiations. If no agreement is reached, the DOJ may decide to file a lawsuit on behalf of the U.S. government against the discriminatory party. Even if someone is not a party to the suit, it can still lead to them being financially compensated.⁸⁸

⁸⁵ It's 300 days if there is a state or local antidiscrimination law that covers the complaint.

⁸⁶ “Frequently Asked Questions,” U.S. EEOC, n.d., last accessed June 14, 2024, <https://www.eeoc.gov/youth/frequently-asked-questions#:~:text=After%20you%20file%20a%20job,to%20resolve%20the%20matter%20quickly>.

⁸⁷ “Questions and Answers,” U.S. DOJ.

⁸⁸ “How to Report a Civil Rights Violation,” U.S. Department of Justice, accessed June 14, 2024, <https://civilrights.justice.gov/#crt-landing--reporting>.

Department of Housing and Urban Development (HUD)

HUD is responsible for enforcing the Fair Housing Act; under its purview, the Office of Fair Housing and Equal Opportunity (FHEO) handles the complaints. If someone has been discriminated against by a public or private landlord, including those that receive Housing Opportunities for Persons with AIDS (HOPWA) funding, they can file a complaint at <https://www.hud.gov/>. This must be done within a year from the last date of alleged discrimination. “[Then] [w]here appropriate, FHEO will draft a formal allegation, have the individual review and sign the allegation, and notify the parties that an allegation has been filed.”⁸⁹

Once a formal allegation is filed HUD will investigate, and the FHEO will send the complainant a written report of its findings. If it finds that no discrimination occurred, the person can file an appeal with the director of the FHEO. If it makes a finding of discrimination, FHEO will issue a Determination of Reasonable Cause and a Charge of Discrimination. The person has 20 days from that finding to decide if they want their case to go in front of a HUD administrative law judge (ALJ), at which they would be represented by HUD, or if they want to pursue a federal lawsuit, which may get filed by the DOJ. Either way, they can also choose to hire their own attorney. Potential outcomes of an ALJ case are “[1] Compensation for your actual damages, including out-of-pocket expenses and emotional distress damages; [2] Permanent injunctive relief, such as an order not to discriminate; [3] Appropriate equitable relief, such as making housing available to you; [4] Payment of reasonable attorney’s fees if you hired a private attorney; [5] Payment of a civil penalty to vindicate the public interest.”⁹⁰

Long-Term Care Ombudsman Program

The Long-Term Care Ombudsman Program is mandated under the OAA (Title VII, Chapter 2, Sections 711/712) but operated and run through the states. Every state has an office supported by local offices at which residents of long-term care facilities can file complaints related to their safety, health, and welfare. Ombudsman programs must often handle complaints that relate to improper eviction or inadequate discharge/planning, lack of respect for residents, poor staff attitudes, or hazardous building conditions.⁹¹ A person can find their state and local ombudsman, along with information on how to file a complaint, here: https://theconsumervoice.org/get_help.⁹²

⁸⁹ “Learn about FHEO’s Process to Report and Investigate Housing Discrimination,” Housing and Urban Development, accessed June 14, 2024, https://www.hud.gov/program_offices/fair_housing_equal_opp/complaint-process.

⁹⁰ “Learn about FHEO’s,” HUD.

⁹¹ “Long-Term Care Ombudsman Program,” Administration for Community Living, last updated July 5, 2023, <https://acl.gov/programs/Protecting-Rights-and-Preventing-Abuse/Long-term-Care-Ombudsman-Program>.

⁹² *Find the Long-Term Care Ombudsman Program in Your State*, The National Consumer Voice, accessed June 14, 2024, https://theconsumervoice.org/get_help.

How Can Advocates Improve Access to Remedies?

Due to PLAHIV's intersectional identities, and therefore the multiple kinds of institutional stigma and discrimination they face, there are a vast range of laws and statutes that impact and control their lives and dictate what is considered discrimination and what recourse they have for addressing it. Two areas of advocacy to highlight are the 2024 reauthorization of the Older Americans Act and the Long-Term Care Bill of Rights.

The Older Americans Act

The OAA is due to be reauthorized in 2024, and while the rules that were issued directed that PLAHIV and LGBTQ+ people be considered groups with greatest social needs, that is not within the text of the statute itself. Having that status made a part of the reauthorized act would protect it from being more easily changed at times of political transition in the executive branch of the federal government. It would also mean that the states are required to view them as such and, therefore, direct resources and attention to the issues faced by PLAHIV. In light of the ongoing political climate in many states, federal mandates are of great importance.

More than 30 states have specific laws that target people living with HIV or have them incur additional penalties/sentence enhancements.⁹³ Currently, dozens of states have antitrans bills that have passed or are pending. If left up to the discretion of the states, the nation will be left with a patchwork system of states where the needs of LGBTQ+ people and PLHIV are prioritized and met, and states where not only are their needs not prioritized but their trans identity or the fact that they are living with HIV could be weaponized against them. Especially in light of the push to collect data to identify needs and trends (which must be safeguarded from misuse by law enforcement), vulnerable populations such as LGBTQ+ older people and PLAHIV must be given as much support and protection as possible.

Similarly, to best serve PLHIV, providers, ombudsmen, and anyone receiving funding through the OAA should be required to receive

LGBTQ+ competency as well as racial justice trainings. Services must be provided in a culturally competent manner or people will simply avoid using the resource. If the intention is to prioritize PLAHIV and LGBTQ+ older people, and the people offering the supportive services are not trained, then the services will not be utilized by the people who are supposed to be prioritized.

In order to prioritize LGBTQ+ older people and those aging with HIV, the definition of family caregiver must be explicitly expanded to include one's "chosen family."

In order to prioritize LGBTQ+ older people and those aging with HIV, the definition of family caregiver must be explicitly expanded to include one's "chosen family." This is contemplated by the rules that state, "With this inclusive approach to defining 'family caregiver,' we include those populations specified in the National Family Caregiver Support Program, as set forth in Title III–E of the Act. For example, this includes unmarried partners, friends, or neighbors caring for an older adult." But it is important that the inclusion of chosen family be explicitly spelled out instead of referring to other statutes, as the rules do, or leaving requirements up to interpretation. Oftentimes, to not be explicitly mentioned by a law means to be found wanting

⁹³ Center for HIV Law and Policy, *Map: HIV Criminalization in the United States*, last updated June 28, 2022, from <https://www.hivlawandpolicy.org/resources/map-hiv-criminalization-united-states-chlp-updated-2022>.

Model Legislation in New York Protects LGBTQ+ and PLHIV in Long-Term Care Facilities

In November 2023, New York joined the small contingent of states and localities (New Jersey, California, Washington DC, and Montgomery County, Maryland) to pass an LGBTQ+ and HIV Long-Term Care Bill of Rights. This bill can serve as model legislation for similar efforts nationally. There are many antidiscrimination laws whose reach touches the care that a PLAHIV would receive in a nursing home.

During the debate on this bill, it was made clear that it went above and beyond the existing protections under New York’s Gender Expression Nondiscrimination Act.

For example, Section III of the ADA specifically forbids discrimination based on disability, including HIV status, in public accommodations.¹ However, the New York LGBTQ+ and HIV Long-Term Care Bill of Rights goes beyond just prohibiting discrimination, by mandating proactive steps to promote culturally competent care and identifying specific areas of conduct that must be addressed to make sure that older LGBTQ+ people and PLAHIV are treated with dignity in care facilities.

During the debate on this bill, it was made clear that it went above and beyond the existing protections under New York’s Gender Expression Nondiscrimination Act (GENDA).² Based on a person’s actual

or perceived sexual orientation, gender identity or expression, or HIV status, under the eight main provisions of the Bill of Rights, the long-term care facilities and/or staff:

1. Cannot deny admission, discharge, or transfer someone
2. Cannot deny request by residents to share a room
3. Must honor a transgender resident’s wishes on where to be assigned a room in facilities that assign rooms by gender
4. Cannot prohibit a resident from using a bathroom of their choice regardless of appearance, surgical status, or hormone use
5. Cannot willfully and repeatedly fail to use resident’s preferred pronouns
6. Cannot limit what a resident wears (unless generally applied)
7. Cannot restrict access to visitors or consensual expressions of intimacy (unless general policy)
8. Cannot restrict access to appropriate medical or nonmedical care (e.g., haircuts)³

The Bill of Rights also establishes procedures for grievances and record keeping. Lastly, it mandates regular cultural competency training for all staff.

¹ 28 C.F.R 36.104 (2010).

² Lesbian, Gay, Bisexual, and Transgender and People Living with HIV Long-Term Care Facility Bill of Rights, A00372-A, June 9, 2023.

³ NY Public Health Law § 2803-c-2.

if a challenge is ever levied. Informal, chosen family caregiving is more in demand due to the fear of experiencing anti-LGBTQ+ bias in congregate care. It is imperative that the definition encompass the reality of LGBTQ+ peoples' lives. Including "chosen family" in the definition of family caregiver gives LGBTQ+ people access to resources and support under the Older Americans Act that they would not otherwise have.

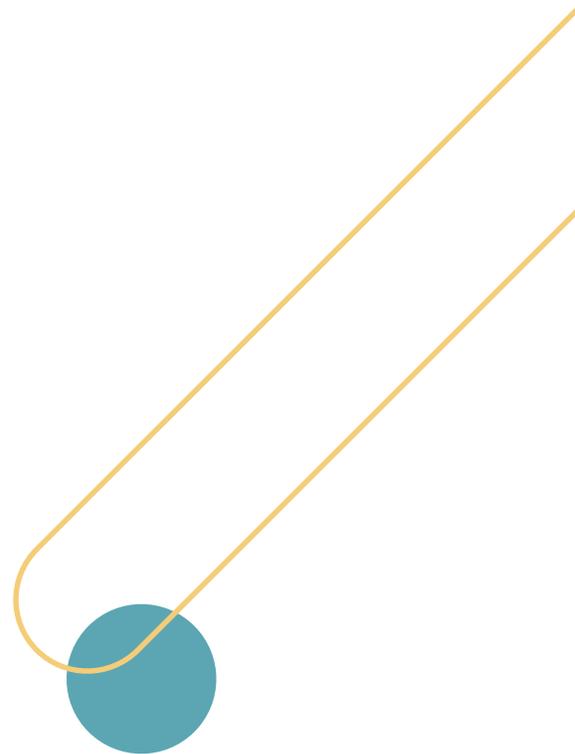
The text of the Older Americans Act emphasizes repeatedly that officials at all levels of programs administered under the act must focus their efforts on supporting "low-income" people. These efforts may be for naught in many areas due to the collateral consequences of criminal records. Having a criminal record can bar people from all kinds of public benefits, varying by state. Similarly, people who had extended incarceration(s) may be unable to meet the requirements to participate in public programs, for example because of not having the work history necessary to qualify for Social Security. It is important, wherever possible, to mandate that a person's criminal history cannot be used as a factor for access to programs funded under the Older Americans Act. This could ameliorate some of the disenfranchisement for people caused by other government programs that fall under other statutes.

LGBTQ+ and HIV Long-Term Care Bill of Rights

At the state level, advocates can push for a LGBTQ+ and HIV long-term care bill of rights.⁹⁴ There is a federal long-term care bill of rights, but it does not explicitly extend its protections to LGBTQ+ older people or PLAHIV.⁹⁵ "LGBTQIA+ older people experience high rates of discrimination, harassment, and abuse based on sexual orientation and gender identity in long-

term care settings. LGBTQIA+ older people are more reliant on formal social services, such as long-term care facilities, than their non-LGBTQIA+ counterparts. As such, they enter long-term care facilities at higher rates and are more vulnerable to discrimination."⁹⁶

Similarly, PLAHIV still face discrimination in long-term care facilities due to their HIV status.⁹⁷ Long-term care bills of rights that explicitly mention both groups are necessary to expand on the protections of the federal Bill of Rights. Statutes have been passed in San Francisco, California, Washington DC, Montgomery County (Maryland), New Jersey, and New York that include LGBTQ+ and PLAHIV.⁹⁸ Many PLAHIV are at their most vulnerable when living in a nursing home, and it is imperative to make sure they have the most support and protection possible.



⁹⁴ SAGE, a leader in this movement, has published a toolkit that may be of use to advocates. SAGE, *LGBTQ+/HIV Long-Term Care Bill of Rights Toolkit*, 2021, <https://www.sageusa.org/wp-content/uploads/2021/09/ltc-bor-toolkit-hapac-v2-logos.pdf>.

⁹⁵ Eleanor Holzman, "Protecting the Forgotten: Enacting an LGBTQIA+ Long-Term Care Bill of Rights," *Tex. J. on C.L. & C.R.* 28 (Spring 2023): 273.

⁹⁶ Holzman, "Protecting the Forgotten," 275.

⁹⁷ "6 Nursing Homes Accused of HIV Discrimination," *POZ*, September 21, 2016, <https://www.poz.com/article/6-nursing-homes-accused-hiv-discrimination>.

⁹⁸ SAGE, *LGBTQ+/HIV Long-Term Care Bill of Rights Toolkit*.

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“Between 1990 and 2005, a new prison opened in the United States every 10 days. Prison growth and the resulting “prison-industrial complex” — the business interests that capitalize on prison construction — made imprisonment so profitable that millions of dollars were spent lobbying state legislators to keep expanding the use of incarceration to respond to just about any problem. Incarceration became the answer to everything....

Never before had so much lobbying money been spent to expand America’s prison population, block sentencing reforms, create new crime categories, and sustain the fear and anger that fuel mass incarceration than during the last 25 years in the United States.”

**BRYAN STEVENSON
*JUST MERCY: A STORY OF JUSTICE AND REDEMPTION*¹**

¹ Bryan Stevenson, *Just Mercy: A Story of Justice and Redemption* (New York: Spiegel & Grau, 2014), 260.



Collateral Consequences of HIV Criminalization

More people are incarcerated in America today than in *any* other country or at *any other* time. The population of incarcerated Americans is also getting older.² An incarcerated person is considered “aging” when they reach the age of 50 or 65, depending on the jurisdiction. By 2030 more than one-third of incarcerated people will be classified as aging.³

Two factors contribute to the overall aging of the population currently incarcerated. The first is longer prison sentences. The duration of incarceration deemed necessary by society for a person to have “served their time” has become longer and longer. As a result, many people are getting older and dying in prisons that are ill equipped to provide the care they need.⁴ The second factor is that people are being convicted and then sentenced to prison at more advanced ages. “According to Human Rights Watch, from 2007 to 2010, the increase in older adults, 65 and up, being sentenced to state and federal prison outpaced the increase in the total population by 94 to 1.”⁵ Arguably, this is another result of tough-on-crime policies that prioritize serving sentences over compassion for the struggles faced by America’s underresourced and underserved older people. Regardless of a

person’s age when they committed a crime, what benefit to society, or retributive purpose for punishment, is served by keeping someone incarcerated after they develop Alzheimer’s or other age-related diseases?⁶

Two factors contribute to the overall aging of the currently incarcerated. The first is longer prison sentences. The second is people are being convicted and then sentenced to prison at more advanced ages.

These tough-on-crime policies mean that people with previous convictions from their youth — the collateral consequences of which they may have been grappling with for decades — now have to learn to navigate services specifically for older people that are not set up to be accessible to them. “Seventy-eight million people have an old criminal record. For anyone among the estimated 45 million people with at least one past misdemeanor conviction, or the nearly 20 million with a past felony conviction, a past record becomes a significant destabilizing factor.”⁷

² Michael Ollove, “Elderly Inmates Burden State Prisons,” *Stateline*, June 6, 2023, <https://stateline.org/2016/03/17/elderly-inmates-burden-state-prisons>.

³ Dominique Ritvo, “The Leftover: Where Do Elderly Prisoners Go When Released?,” *Elder Law Journal* 26, no. 1 (2018): 230.

⁴ Jamie Fellner, *Old Behind Bars: The Aging Prison Population in the United States*, Human Rights Watch, January 27, 2012, <https://www.hrw.org/report/2012/01/28/old-behind-bars/aging-prison-population-united-states>. The aging of the prison population has caused prisons in many states to create internal “assisted living” wings, nursing homes, and even entire prisons dedicated to caring for aging prisoners.

⁵ Ollove, “Elderly Inmates.”

⁶ Fellner, *Old Behind Bars*, 93.

⁷ *Toward Stability and Safety: Experiences of People with Old Criminal Records*, Alliance for Safety and Justice, August 2021, <https://allianceforsafetyandjustice.org/wp-content/uploads/2021/09/Convictions-Brief.pdf>.

These policies are also a barrier to previously incarcerated peoples' ability to access public benefits. The time that has passed since the conviction does not typically matter when governmental or private entities are making benefit eligibility determinations. Once enmeshed in the criminal legal system, people are rarely, if ever, truly done "serving their time." For example, under the 1996 Personal Responsibility and Work Opportunity Reconciliation Act, states were required to ban those convicted of state or federal drug crimes from receiving Temporary Assistance for Needy Families (TANF) and food stamps for life. However, states could choose to opt out of the lifetime bans by passing legislation and most did so over time, although some states chose to leave shorter-term bans in place.⁸ Also, although there are only two kinds of convictions under The Office of Housing and Urban Development's (HUD) rules that mandate a person's permanent exclusion from federally subsidized housing, local housing authorities have wide latitude in determining what convictions to take into account when they are making eligibility determinations.

Beyond the legal limitations and barriers arising from the collateral consequences that encircle the previously incarcerated, having been imprisoned has a profound impact on, and is a social determinant of, a person's health. In fact, for both men and women, experience with incarceration has been shown to be strongly associated with rates of HIV.⁹ It should be noted that it is difficult, if not impossible, to tell if it is the social conditions and systemic barriers

that make groups in the United States targets of incarceration or the incarceration itself that is at the "root" of the connection between incarceration and HIV. Nevertheless, that correlation exists. "[T]he populations at risk of HIV and the populations that are incarcerated — including people who use drugs, sex workers, the poor, the homeless, and racial and ethnic minorities — overlap in the U.S. The prevalence of HIV among incarcerated persons is three times greater than in the general population. One out of seven people living with HIV will enter a jail or prison each year."¹⁰

Once a person is released, the impact of a prior incarceration only increases that person's vulnerability to acquiring HIV. "In particular, incarceration affects social networks and family relationships, economic vulnerability, and access to social and risk reduction services."¹¹ It is important to emphasize that the increased rates of HIV among those who were previously incarcerated are not a result of their choices or their perceived "moral failings" but are instead a direct result of the systems of oppression that limit their access to support services. For example, studies show that although Black people have a much higher rate of HIV acquisition than their white counterparts, they typically are less likely to have engaged in behaviors, such as condomless sex or intravenous drug use, that are known modes of HIV transmission.¹² The next section will explore some of the systemic conditions and barriers that lead to a disproportionate number of People Living and Aging with HIV (PLAHIV) being likely to have a criminal record.

⁸ Kim M. Blankenship et al., "Black-White Disparities in HIV/AIDS: The Role of Drug Policy and the Corrections System," *Journal of Health Care for the Poor and Underserved* 16, no. 4B (January 1, 2005): 140–46, <https://pubmed.ncbi.nlm.nih.gov/16327113/>; Jimmie E. Gates, "Drug Felons Can Now Receive Food Stamps in Mississippi," *Mississippi Clarion Ledger*, May 1, 2019, <https://www.clarionledger.com/story/news/politics/2019/05/01/snap-mississippi-removes-drug-felony-ban-receiving-food-stamps/3592098002>; Ashley Burnside, *No More Double Punishments: Lifting the Ban on SNAP and TANF for People with Prior Felony Drug Convictions* (CLASP, April 19, 2023), <https://www.clasp.org/publications/report/brief/no-more-double-punishments>.

⁹ Bryan L. Sykes et al., "Cruel Intentions? HIV Prevalence and Criminalization During an Age of Mass Incarceration, US 1999 to 2012," *Medicine* 95, no. 16 (April 1, 2016): 2, <https://doi.org/10.1097/md.0000000000003352>.

¹⁰ Megan McLemore, *Paying the Price*, Human Rights Watch, March 28, 2023, 6, <https://www.hrw.org/report/2016/03/29/paying-price/failure-deliver-hiv-services-louisiana-parish-jails#:~:text=Louisiana%20fails%20to%20provide%20basic,communities%20to%20which%20they%20return>.

¹¹ Blankenship, "Black-White Disparities," 140-46.

¹² "Black queer men's behavior doesn't account for our heightened viral risk; we actually have been shown to have fewer sexual partners and engage in less recreational drug use than our white peers. What we have is more exposure to racism and less protection from prophylaxis." Steven W. Thrasher, *The Viral Underclass: The Human Toll When Inequality and Disease Collide* (New York: Celadon Books, 2022), 179; Blankenship, "Black-White Disparities," 140-46.

Why Do People Living and Aging with HIV Have Criminal Records?

The Criminalization of People Living with HIV

One reason that People Living with HIV (PLHIV) have criminal records is the criminalization of HIV. Laws criminalizing HIV began to be passed throughout the United States in the early years of the AIDS epidemic and remain on the books in more than 30 states.¹³ The “criminalization of HIV” refers to laws that make conduct by a PLHIV who knows their status illegal. Such laws not only specifically target PLHIV, but they also include prosecution under the general criminal code, as well as sentencing or other enhancements (increased penalties) that are applied based on someone’s HIV status.¹⁴ For example, in many states, when a sex worker is charged with solicitation and they are aware of their HIV status, the crime is raised from a misdemeanor to a felony. Some states, like Oklahoma or Tennessee, convict someone of engaging in sex work while living with HIV based only on an allegation that they entered into a verbal agreement; no sexual act needs to have taken place.¹⁵ In such cases, the increased penalty is purely due to someone’s HIV status — no conduct that would be capable of leading to HIV transmission has to have happened, and the person’s viral load or engagement in treatment does not matter.¹⁶ Some states, such as Louisiana, even specify that transmission does

not have to have been possible for prosecution under their state’s exposure to HIV statute, only that the individual allegedly knew their status and failed to disclose it to the accuser.¹⁷

Inclusion on the sex offense registry is an additional and grievous penalty that can have significant repercussions for an aging person’s access to services

Inclusion on the sex offense registry is an additional and grievous penalty that can have significant repercussions for an aging person’s access to services.¹⁸ The sex offense registry is not, as many people believe, “just” the Megan’s Law database listing a person’s name, appearance, address, and conviction information so that the public can be aware if someone who was previously convicted of a sex offense lives in their neighborhood. It is a complex web of requirements that vary not only from state to state but often from county to county, town to town, and that a person must adhere to for a lengthy period after their release from prison. Failure to comply with any of these policies often results in conviction for a separate crime and additional prison time. These requirements have even led to situations where the only place far

¹³ *HIV Criminalization in the United States*, CHLP, accessed April 28, 2024, <https://www.hivlawandpolicy.org/sites/default/files/HIV%20Criminalization%20in%20the%20US%2C%20CHLP%20062822.pdf>.

¹⁴ *HIV Criminalization in the United States: A Sourcebook on State and Federal HIV Criminal Law and Practice*, s.v. “Introduction,” CHLP, accessed April 28, 2024, 1, <https://www.hivlawandpolicy.org/sites/default/files/HIV%20Criminalization%20in%20the%20U.S.%20A%20Sourcebook%20on%20State%20Fed%20HIV%20Criminal%20Law%20and%20Practice%20022722.pdf>.

¹⁵ *HIV Criminalization in the United States*, s.v. “Tennessee,” CHLP, accessed April 28, 2024, 5-6.

¹⁶ CHLP, “Tennessee.”

¹⁷ *State v. Gamberella*, 633 So.2d. 595 (La. App. 1 Cir. 1993).

¹⁸ Author acknowledges that the Supreme Court declared that being required to register on a sex offense registry is not a penalty but agrees with Professor Michael Caldwell, “Courts have employed impressive logical gymnastics to avoid calling these laws punishments or to say they don’t count as punitive under the relevant constitutional clauses,” and will therefore call them what they are, a draconian *punishment*. Michael Karlik, “Supreme Court’s Decision on Sex Offender Registry Leaves Some Eyeing a Broader Constitutional Challenge,” *Colorado Politics*, June 29, 2021, https://www.coloradopolitics.com/courts/supreme-courts-decision-on-sex-offender-registry-leaves-some-eyeing-a-broader-constitutional-challenge/article_038ca0b0-d8e5-11eb-aa8c-cb898c997345.html#:~:text=The%20U.S.%20Supreme%20Court%20in,offender%20registration%20protocol%20was%20constitutional.

Discriminatory Enforcement of HIV Criminalization Laws in Louisiana

The general public's profound lack of literacy concerning the actual risks, routes, and realities of treatment for HIV transmission, compounded by moral judgment, homophobia, and racism, continues to fuel the enactment and enforcement of disease-specific punitive criminal laws.¹ More than 30 states and several U.S. territories have laws that call for the prosecution and imprisonment of people living with HIV for conduct that is legal or would be only a minor offense (e.g., spitting on someone) for people not living with HIV.² These laws, and their penalties, are solely a matter of state law — there is no parallel federal crime or penalty.³

In Louisiana, a person can be criminalized for intentionally exposing another person to HIV and it carries the particularly harsh punishment of placement on the sex offense registry. The law specifically criminalizes exposure, not transmission, in order to cast the widest net possible.⁴ Louisiana is one of only five states where sex offense registry is required of those convicted. The Louisiana law is explicitly rooted in a purely “moral” or religious grounding, and not anything scientific. There is no requirement for the

prosecution to prove intent to transmit, or even that the “behavior” engaged in could result in transmission.⁵ If the purported purpose of laws criminalizing people with HIV is to protect the community, but the law does not require a viable threat to the community (i.e., that there is no risk of transmission) then it is possible there is an ulterior motive to the law not explicitly stated.

Louisiana is one of only five states where sex offense registry is required of those convicted.

That ulterior motive was clearly on display in 1987 when the Louisiana HIV criminalization bill, one of the first of its kind, was being debated in the state legislature. The bill's lead sponsor, Representative Kernan Hand, said during a committee hearing that “the purpose of this bill is to deter those infected with [HIV] from remaining sexually active in the community.”⁶ An individual convicted

¹ Bebe J. Anderson, J.D., “HIV Stigma and Discrimination Persist, Even in Health Care,” *JAMA* (Dec. 2009), <https://journalofethics.ama-assn.org/article/hiv-stigma-and-discrimination-persist-even-health-care/2009-12>. Anne L. Stang et al., “The Health Stigma and Discrimination Framework: a Global, Crosscutting Framework to Inform Research, Intervention Development, and Policy on Health-Related Stigmas,” *BMC Medicine* (2019), <https://bmcmmedicine.biomedcentral.com/articles/10.1186/s12916-019-1271-3>.

² The Center for HIV Law and Policy, *HIV Criminalization in the United States* (2022), <https://www.hivlawandpolicy.org/resources/map-hiv-criminalization-united-states-chlp-updated-2022> (last visited December 13, 2022).

³ “An offense involving consensual sexual conduct is not a sex offense for the purposes of this title if the victim was an adult.” 42 U.S.C. 16911(5)(c).

⁴ LA R.S. § 14:43.5 (2018).

⁵ *State v. Gamberella*, 633 So.2d 595 (La. App. 1 Cir. 1993); La. Rev Stat. Ann. § 14:43.5 (2018).

⁶ Nathan Cisneros et al., *Enforcement of HIV Criminalization in Louisiana*, Williams Institute, September 2022, <https://williamsinstitute.law.ucla.edu/wp-content/uploads/HIV-Criminalization-LA-Sep-2022.pdf>; Official Journal of the House of Representatives of the State of Louisiana, 31st Day's Proceedings, 1987 Leg., 13th Reg.Sess. at 1628 (1987).

under this statute in Louisiana faces up to 10 years in prison and sex offense registry, whereas someone convicted of *negligent homicide* faces only 5 years.⁷ The severe punishment levied upon those convicted under this statute not only is stigmatizing but vilifies people living with HIV.

The Williams Institute did a study in Louisiana looking at how HIV criminalization laws have been applied and found extensive evidence of racial discrimination, specifically against Black people.

It is not only the language of the statute that is problematic but the discriminatory way that it has been enforced. There are two ways that laws can be shown to be discriminatory: (1) *de jure* discrimination and (2) *de facto* discrimination. De jure discrimination is also known as facial discrimination because the bias/discriminatory conduct is mandated under the law and therefore appears on its face. De facto discrimination, also called “as applied” discrimination, exists when a law is “facially neutral,” meaning that discrimination is not mandated under the law, but that if you look at how the law is used you can find evidence of discrimination.

The Williams Institute did a study in Louisiana looking at how HIV

criminalization laws have been applied and found extensive evidence of racial discrimination, specifically against Black people. The study found that since 2011, 91% of the people arrested under the state’s HIV criminalization law were Black men, who only make up 41% of all people living with HIV in Louisiana.⁸ Looking at data since 1998, 75% of all registrants on the Louisiana registry due to an HIV-related crime have been Black men.⁹ The laws already single people out for different treatment than others based on their HIV status, making it facially discriminatory. However, the discriminatory targeting of Black people makes that law discriminatory as applied, as well.

⁷ Rachel Brown, “When the Body Is a Weapon: An Intersectional Feminist Analysis of HIV Criminalization in Louisiana,” *Berkeley Journal of Gender, Law, & Justice* 35, no. 1 (2020) (in-depth analysis of the history and impact of the Intentional Exposure to HIV law in Louisiana).

⁸ Cisneros et al., *Enforcement*.

⁹ Cisneros et al., *Enforcement*.

enough away from a school that people on the registry could live was under a bridge.¹⁹ And for older adults who are trying to access public housing, being on the sex offense registry can block their ability to obtain it or can limit their options for care in a private facility.

The people prosecuted under such state laws have typically been, and continue to be, the most marginalized PLHIV. Black people, especially Black trans women and Black men who have sex with men are, unsurprisingly, those primarily targeted. In their reviews of arrests and prosecutions under these laws across the country, researchers at the Williams Institute at UCLA School of Law have found in state after state that Black people face penalties that are disproportionate to their percentage of the population. Sometimes, in states such as Louisiana, they are *the only* people prosecuted under these HIV criminal laws.²⁰ And while numerous states have “modernized” their HIV criminalization laws, with a few repealing them altogether, in many places sentencing enhancements for sex workers remain untouched.²¹ Many states prosecute PLHIV under either HIV-specific laws or the general criminal code. Therefore, not only are these laws a reason why PLAHIV may have a criminal record, they also pose an ongoing risk that PLAHIV will acquire one.²²

The Targeting of Black People by the “War on Crime”

Not only are laws criminalizing PLHIV disproportionately applied to Black people, but this is true of criminal law in general.²³ Statistics show that one in twenty white men will go to prison in their lifetimes versus one in four Black men, demonstrating not just disproportionality but the inherent racism of the criminal legal system.²⁴

The hyper incarceration of Black people combined with high rates of HIV diagnoses among Black people results in the incarceration of a growing number of Black PLHIV.

Because of interlocked systemic barriers placed between them and such necessities as equitable access to healthcare (including access to HIV preventative measures, such as PrEP), Black people represent the fastest-growing racial group with new HIV diagnoses. In 2022, Black people made up 37% of new diagnoses despite being only 12% of the U.S. population.²⁵ Of that 37%, the fastest-growing numbers were from the South, where Black men who had sex with men

¹⁹ Greg Allen, “Sex Offenders Forced to Live under Miami Bridge,” *All Things Considered*, May 20, 2009, <https://www.npr.org/2009/05/20/104150499/sex-offenders-forced-to-live-under-miami-bridge>.

²⁰ Nathan Cisneros et al., *Enforcement of HIV Criminalization in Louisiana*, Williams Institute, September 2022, <https://williamsinstitute.law.ucla.edu/wp-content/uploads/HIV-Criminalization-LA-Sep-2022.pdf>.

²¹ “Timeline of State Reforms and Repeals of HIV Criminal Laws,” The Center for HIV Law and Policy, September 6, 2023, <https://www.hivlawandpolicy.org/resources/timeline-state-reforms-and-repeals-hiv-criminal-laws-chlp-updated-2022>.

²² This risk is potentially exacerbated by the fact that sexual health literacy geared toward older people is almost nonexistent, so they may be unaware of any risks. Many aging people are treated as if they no longer have sex, and this treatment is an underlying reason that older people have one of the fastest growing rates of acquiring HIV. “HIV and Specific Populations,” National Institute of Health, March 12, 2024. <https://hivinfo.nih.gov/understanding-hiv/fact-sheets/hiv-and-older-people#:~:text=According%20to%20the%20Centers%20for,were%20aged%2050%20and%20older>.

²³ In this context, “disproportionate” is not meant to imply that there is a “proportionate” amount to criminalize people, but to refer to statistical evidence of the targeting of Black people by law enforcement. “We cannot ignore the reality that we live in a white supremacist society and in a white supremacist society, the notion of criminality, disposability and guilt will always maintain Blackness and those in the closest proximity to Blackness as culpable.” S. Mandisa Moore-O’Neal, “What Does Abolition Have to Do With HIV Decriminalization and Modernization? Working to Free Us All,” *Positively Aware*, October 29, 2020, <https://www.positivelyaware.com/articles/what-does-abolition-have-do-hiv-decriminalization-and-modernization>.

²⁴ Bruce Western et al., “Incarceration & Social Inequality,” *Daedalus* 139, no. 3 (2010): 10, <https://www.amacad.org/publication/incarceration-social-inequality>.

²⁵ “Fast Facts: HIV in the US by Race and Ethnicity,” Centers for Disease Control and Prevention, June 26, 2023, <https://www.cdc.gov/hiv/data-research/facts-stats/race-ethnicity.html#:~:text=At%20a%20glance,new%20HIV%20infections%20in%202022>.

and Black transgender women had the highest rates of diagnosis.²⁶ The disproportionate impact of HIV on the Black community in the United States is not a new phenomenon. While the face of the HIV epidemic has consistently been a white gay man, the hardest hit group has consistently been Black people.

Incarceration, and its impact on life after release, is also correlated with a higher chance of acquiring HIV. The hyperincarceration of Black people combined with high rates of HIV diagnoses result in the incarceration of a growing number of Black PLHIV. Writing about these disparities, the researcher Kim Blankenship states:

African Americans in the United States are disproportionately affected by HIV/AIDS. We focus in this paper on the structural and contextual sources of HIV/AIDS risk, and suggest that among the most important of these sources are drug policy and the corrections system. In particular, high rates of exposure to the corrections system (including incarceration, probation, and parole) spurred in large part by federal and state governments' self-styled war on drugs in the United States, have disproportionately affected African Americans.²⁷

Add to this overlap both the rising percentage of people over the age of 50 living with HIV and the aging of the prison population, and it is clear that a large percentage of PLAHIV have criminal records and are thus impacted by the ongoing collateral consequences.

The Targeting of LGBTQ+ People

LGBTQ+ people have a higher likelihood than the rest of the population of being incarcerated in their lifetimes.²⁸ The targeting of LGBTQ+ people is rooted in a long history of violence against LGBTQ+ communities committed by the legal system. Their existence has been criminalized by a network of laws ranging from early 20th-century sumptuary laws that regulated dress and appearance to sodomy laws that are still on the books in many states and were only recently rendered unconstitutional. As discussed earlier, Black and brown LGBTQ+ people have a higher probability of interaction with the criminal legal system than do white LGBTQ+ people because they are also targeted by law enforcement based on race. Many of the LGBTQ+ people who are convicted of crimes are also PLHIV.

LGBTQ+ people, especially Black and brown transgender people, come into contact with law enforcement because they rely on survival crimes, such as theft or sex work, to deal with the repercussions of transphobia, homophobia, and/or racism in their lives. For example, transgender youth, who are often kicked out of their homes because of their gender identity, are disproportionately experiencing homelessness, with 20% to 40% of youth experiencing homelessness identifying as LGBTQ+.²⁹ This often leads these young people to engage in survival crimes so that they can obtain some sort of shelter.³⁰ In fact, family rejection and homelessness have been found to be the top predictors that an LGBTQ+ youth will end up in the criminal justice system, especially because of the heavy police

²⁶ Linda Villarosa, *Under the Skin: The Hidden Toll of Racism on American Lives and on the Health of Our Nation* (New York: Doubleday, 2022), 164.

²⁷ Blankenship, "Black-White Disparities," 140-46.

²⁸ Nazgol Ghandnoosh, Ph.D. et al., *Incarcerated LGBTQ+ Adults and Youth* (The Sentencing Project, 2022), <https://www.sentencingproject.org/app/uploads/2022/10/Incarcerated-LGBTQ-Youth-and-Adults.pdf>.

²⁹ Katayoon Majd, *Hidden Injustice: Lesbian, Gay, Bisexual, and Transgender Youth in Juvenile Courts* (Models for Change, 2009), 71, https://www.modelsforchange.net/publications/237/Hidden_Injustice_Lesbian_Gay_Bisexual_and_Transgender_Youth_in_Juvenile_Courts.pdf. Finding transgender-specific data can be difficult as the "T" is normally lumped in with the "LGB."

³⁰ Majd, *Hidden Injustice*, 4.

surveillance of the disproportionately LGBTQ+ population experiencing homelessness.³¹

Transgender women living with HIV have a particularly high risk of being impacted by the criminal legal system.

Forty-one percent of all transgender women reported an interaction with the criminal justice system, which was a significantly higher rate than cisgender women (23%). This included having a sex partner threaten to contact the police, being accused of committing a crime, being arrested, being criminally prosecuted, receiving a sentence, probation, and/or reporting incarceration for a week or more. Among incarcerated

transgender women, 56% reported experiencing problems related to their HIV during that time.³²

The targeting of trans women by the criminal legal system is so pervasive that the phrase “walking while trans” has been coined to describe the criminalization of merely appearing transgender.³³ The criminal legal system’s targeting of LGBTQ+ people, especially Black men who have sex with men and Black trans women, combined with the impact of homophobia and transphobia on their lives, which forces many to turn to survival crimes, means that a large number of LGBTQ+ PLHIV also have criminal records.

Collateral Consequence: Housing Instability

People face myriad collateral consequences after they finish their terms of criminal legal supervision, ranging from limitations on getting a haircutting license to felony bars against voting. One issue plaguing the entire country, and of significant increase and concern for aging people, is the dearth of affordable housing. Having a criminal record can seriously constrain the ability to find and to remain in stable housing, both in subsidized housing (where the government or a program pays a portion of one’s rent) and in the private market. There are many reasons for the housing crisis faced by older people. These range from the inability of people on a fixed income to meet rising rents caused

by gentrification in their neighborhoods to the age and condition of affordable housing stock that often cannot accommodate the physical needs or mobility constraints that aging people may have. Alternatives such as assisted living that are far beyond the ability of lower-income individuals to afford worsen this crisis.³⁴ Experts nationwide agree that homelessness among older Americans is steeply on the rise and will only worsen — in some cities, such as Los Angeles and Boston, it will triple by 2030.³⁵

A huge issue for PLHIV across the age spectrum, “housing instability” is an umbrella term that encompasses a variety of conditions. These can include paying more than 30% of a household’s

³¹ Catherine Hanssens et al., *A Roadmap for Change: Federal Policy Recommendations for Criminalization of LGBT People and People Living with HIV*, New York: Center for Gender & Sexuality Law at Columbia Law School, 2014, 4, https://hivlawandpolicy.org/sites/default/files/Roadmap_For_Change_full_report.pdf.

³² Ayako Miyashita, *The Legal Needs of People Living with HIV: Evaluating Access to Justice in Los Angeles*, Williams Institute, April 28, 2020, 11-12, <https://williamsinstitute.law.ucla.edu/publications/legal-needs-people-living-hiv>.

³³ Masen Davis, “Gender Freedom and Self Expression,” interview by Racial Equity, *Racial Equity*, <http://www.lgbtracialequity.org/perspectives/perspective.cfm?id=21>. “Walking while trans” refers to police targeting of trans women for arrest as sex workers; Juhu Thukral, Esq. et al., *Revolving Door: An Analysis of Street-Based Prostitution in New York City*, Urban Justice Center, 2003, 36-37, <http://www.sexworkersproject.org/downloads/RevolvingDoor.pdf>.

³⁴ “There’s no single reason for the rise in the older homeless population. Weak social safety nets, mass incarceration policies and an insufficient supply of affordable housing are among the many factors, according to Kushel, Culhane and other experts.” Hannah Grabenstein, “More Seniors Are Becoming Homeless, and Experts Say the Trend is Likely to Worsen,” *PBS News Hour*, March 3, 2023, <https://www.pbs.org/newshour/nation/more-seniors-are-becoming-homeless-and-experts-say-the-trend-is-likely-to-worsen#:~:text=There's%20evidence%20that%20the%20wave,people%20in%20the%20boomer%20generation>.

³⁵ Grabenstein, “Seniors Becoming Homeless.”

income for rent or a mortgage, having trouble paying rent, overcrowding, couch surfing, moving frequently, and being able to rent only subpar housing.³⁶ A large percentage of PLHIV struggle with housing instability at some point in their lives. One CDC study from 2021 showed that 17% of PLHIV had recently experienced homelessness or some other form of unstable housing.³⁷ The same study also found that among PLHIV who needed housing services, anywhere from 20% to 60% did not have those needs met.³⁸ Of the people who identify as lacking housing, 51% report the reason is simply their not being able to find the information they require.³⁹ Moreover, rates of unstable housing for aging PLHIV are not consistent across race and gender, with Black men and Black transgender people having the highest rates of being

One CDC study from 2021 showed that 17% of PLHIV had recently experienced homelessness or some other form of unstable housing.

unstably housed.⁴⁰ Access to housing is also a social determinant of health as unstable housing makes it more difficult, if not impossible, for many PLAHIV to address their medical needs.

Housing instability impacts aging people, including aging PLHIV, differently than it impacts the younger population. Couch surfing, for

example, may not be an option for an older person that requires accommodations (such as an absence of stairs) for their more complex physical needs. An older person may have fewer people to rely on or may not want to be a burden on their adult children or friends.⁴¹

For older people leaving incarceration or living with an old conviction, the search for housing is even more constricted.⁴² This can be true for those seeking housing in the landlord/tenant market as well as for those who need the level of care available at a nursing home.⁴³ Unfortunately, unstable housing has also been shown to leave people who have criminal records vulnerable to rearrest, in part because they may be forced into recidivism (committing new crimes) in order to care for themselves.⁴⁴

WHAT HOUSING OPTIONS DO EXIST (AND HOW DO THEY TAKE INTO ACCOUNT CRIMINAL RECORDS)?

A vast array of housing types and services are available for people who are aging, and most of these are *technically* open to all people, regardless of whether they have a criminal record. According to U.S. Department of Housing and Urban Development guidance, housing providers, including private landlords, cannot have blanket bans against allowing anyone with a criminal record to reside in their housing, as to do so would violate the 1968 Fair Housing Act.⁴⁵ Under the Fair Housing Act, housing providers cannot discriminate against people on the basis of race, disability and other protected classes.⁴⁶

³⁶ "Housing Instability," OASH: Healthy People 2030, n.d., <https://health.gov/healthypeople/priority-areas/social-determinants-health/literature-summaries/housing-instability>.

³⁷ Sharoda Dasgupta et al., "Needs for Shelter or Housing Assistance among People with Diagnosed HIV by Jurisdiction: United States, 2015–2020," *AIDS* 37, no. 3 (December 23, 2022): 536, <https://doi.org/10.1097/qad.0000000000003460>.

³⁸ Dasgupta et al., "Needs for Shelter," 535.

³⁹ Dasgupta et al., "Needs for Shelter."

⁴⁰ Mark Brennan-Ing et al., "Aging with HIV: Health Policy and Advocacy Priorities," *Health Education & Behavior* 48, no. 1 (January 7, 2021): 6, <https://doi.org/10.1177/1090198120984368>.

⁴¹ Grabenstein, "Seniors Becoming Homeless."

⁴² Ritvo, "Leftover."

⁴³ Christie Thompson, "Ever Committed a Crime? Good Luck Finding a Place to Live," *Think Progress*, July 1, 2014, <https://archive.thinkprogress.org/ever-committed-a-crime-good-luck-finding-a-place-to-grow-old-f5151341a095/>.

⁴⁴ Valerie Schneider, "The Prison to Homelessness Pipeline: Criminal Record Checks, Race, and Disparate Impact," *Indiana Law Journal* 93, iss. 2 (2018): 432, <https://www.repository.law.indiana.edu/cgi/viewcontent.cgi?article=11290&context=ilj>.

⁴⁵ HUD Office of General Council, *Guidance on Application of Fair Housing Act Standards to the Use of Criminal Records by Providers of Housing and Real Estate-Related Transactions* (April 4, 2016), https://www.hud.gov/sites/documents/HUD_OGCGUIDAPPFHASTANDCR.PDF.

⁴⁶ For a more extensive discussion of the Fair Housing Act please see page 16.

Owing to the disparate impact of the criminal legal system on Black and brown people, having a blanket ban against anyone with a criminal record would violate this limitation.⁴⁷ Beyond forbidding an outright ban, little or no protection exists for people with a record who are looking to rent on either the private or the subsidized market. There do exist several categories of subsidized housing options for those with a criminal record looking for a place to live, with some specifically designated for older people.⁴⁸

Private Market Housing

Private housing is what most people think of when they talk about renting from a landlord. It is simply residing in a property owned by another with their permission, with or without a written lease, and it likely includes the requirement to pay some sort of rent to the owner. Renting on the private market can be difficult for people with criminal records. First, there is the impact of the criminal record itself on the likelihood of securing housing. Even though blanket bans by landlords are not permitted, showing that one has been the victim of a discriminatory housing ruling can be difficult if not impossible without a specific act or word to point to that proves that they would have been permitted to rent if it were not for their record. Providing information to landlords about prospective tenants regarding criminal records (among other things) is a big business.⁴⁹ Another piece of information that landlords are

interested in, and that someone with a history of incarceration might have a problem with, is a prospective renter's credit score. After being incarcerated, especially for a long time, a person is unlikely to have a lengthy or strong credit history due to the inability to build one while in prison. Similarly, the person, while incarcerated, may not have been able to save enough to afford a security deposit and other substantial move-in expenses.

Assisted Living

“Assisted living facilities offer a combination of housing, supportive services and personal care (not including medical care) that enables older people to maintain maximum independence while receiving the assistance they need. While assisted living has become an increasingly popular option with upper- and middle-income people, the high costs put it out of reach for low- to moderate-income groups.”⁵⁰ The average cost of assisted living is \$3,000 to \$6,000 per month depending on where someone lives.⁵¹ There are options for subsidizing this exorbitant cost, such as Section 202, Veteran Benefits, and Medicaid, but they typically do not bring the cost down enough to be truly “affordable.” Most costs are paid for by the older people themselves.⁵² Also, many facilities are not equipped to deal with the complex medical needs of PLAHIV.⁵³ As for people with criminal records who are aging with HIV, many assisted living facilities may not

⁴⁷ *Fair Housing for People With a Criminal Record: A Digital Toolkit*, Fair Housing Center for Rights & Research, 2022, <https://www.thehousingcenter.org/wp-content/uploads/2022/09/FAIR-HOUSING-FOR-PEOPLE-WITH-A-CRIMINAL-RECORD-A-DIGITAL-TOOLKIT.pdf>.

⁴⁸ This primer focuses on the impact on renters, not homeowners or those seeking a path to homeownership. In most contexts, when a “lack of affordable housing” is discussed, it is largely a discussion of renters and skyrocketing rent costs.

⁴⁹ “One company, for example, boasts in its brochure that it is capable of combining criminal, proprietary, and credit data for over ‘200 million convictions associated with more than 62 million unique individuals, to which it adds approximately 22,000 new records daily.’ Another company gives landlords access to over ‘200+ million criminal records’ from state and national databases within minutes.” Schneider, “Homelessness Pipeline,” 428-29.

⁵⁰ Jenny Scheutz, *Affordable Assisted Living: Surveying the Possibilities*, Joint Center for Housing Studies of Harvard University, January 2003, 5, https://www.jchs.harvard.edu/sites/default/files/media/imp/03-1_schuetz.pdf.

⁵¹ “Assisted Living Options for Low Income Elders,” assistedliving.org, last updated August 26, 2022, <https://www.assistedliving.org/assisted-living-near-me/assisted-living-options-low-income-elders/>.

⁵² *Black and Aging in America 2021*, National Caucus and Center on Black Aging, Inc., 2020, https://ncba-aging.org/wp-content/uploads/2023/01/FINAL-NCBA_Black_Aging_America_Digital_web47.pdf.

⁵³ Katja Heineman, *The Graying of AIDS: Stories From an Epidemic*, SAGE, January 2005, <https://lgbtagingcenter.org/library/item/the-graying-of-aids-stories-of-an-aging-epidemic/>. These complex medical needs are not necessarily HIV care itself but instead many conditions that have been found to be more prevalent in PLAHIV.

be an option, as they screen out people on the basis of their past convictions.⁵⁴

Nursing Homes

Nursing homes are equipped to provide a level of care for people beyond that available at assisted living facilities. This level of care is designed specifically to meet the medical and personal care needs of those unable to perform tasks of daily living without assistance.⁵⁵ Nursing homes are typically more expensive than assisted living facilities and are more heavily subsidized by the Medicaid public benefit program. This, coupled with the generally low incomes of older people living with HIV, means that many PLAHIV may find themselves placed in nursing homes long before they require that level of care.⁵⁶ This is a particularly relevant issue for Black elders, who are disproportionately subject to pre-need placement in nursing homes.⁵⁷ As with assisted living facilities, nursing homes screen applicants for criminal records and commonly reject people on that basis.⁵⁸ Rejection may occur even when the criminal record is from years earlier and even if the person would no longer be capable of committing the crime for which they were previously incarcerated based on their current physical and/or mental condition.⁵⁹ The refusal of many nursing homes to accept people with criminal convictions can lead to the continued incarceration of individuals who, because of their complex medical needs, would otherwise qualify for early or compassionate release. This

Many people living with HIV find themselves placed in nursing homes long before they require that level of care — a particularly relevant issue for Black elders, who are disproportionately subject to pre-need placement in nursing homes.

can include incarcerated PLAHIV because those advocating for their release can find no facility that will accept them.⁶⁰

Subsidized Housing

Subsidized housing means that the government (federal, state, city, etc.) or some other program or organization pays a percentage of a person's rent (up to 100%) or charges a person rent for housing calculated as a percentage of the individual's total income. There are many kinds of programs that specialize in housing a variety of populations either permanently or for a limited time. These programs may be run not only by the state but also by localities or municipalities.⁶¹ However, some subsidized housing programs are available nationally, both for PLAHIV and for aging people generally, typically overseen by HUD.

Access to subsidized housing is generally based on income, although different programs have different income ceilings, and many older people

⁵⁴ Ritvo, "Leftover," 254.

⁵⁵ "Long-Term Care Facilities: Assisted Living, Nursing Homes, and Other Residential Care," National Institute on Aging, October 12, 2023, <https://www.nia.nih.gov/health/assisted-living-and-nursing-homes/long-term-care-facilities-assisted-living-nursing-homes#nursing>.

⁵⁶ Denny Chan et al., *The Economic Security and Health of Older Women of Color*, Justice in Aging, June 2023, 22, <https://justiceinaging.org/wp-content/uploads/2023/07/The-Economic-Security-and-Health-of-Older-Women-of-Color-IssueBrief-FINAL.pdf>; *Supporting the Economic Security and Health of Older Women of Color*, National Women's Law Center, September 2021, 5, <https://nwl.org/resource/supporting-the-economic-security-and-health-of-older-women-of-color/>.

⁵⁷ National Caucus and Center on Black Aging, Inc., *Black and Aging*.

⁵⁸ Fellner, *Old Behind Bars*, 80.

⁵⁹ Jennifer Kye, *Fair Housing Protections for Formerly Incarcerated and Justice-Involved Older Adults*, Justice in Aging, November 2023, <https://justiceinaging.org/wp-content/uploads/2023/11/Fair-Housing-Protections-for-Formerly-Incarcerated-and-Justice-Involved-Older-Adults.pdf>.

⁶⁰ Hope Corrigan, "Why Elderly Incarcerated People Struggle to Find Care After Prison," *The Appeal*, July 18, 2022, <https://theappeal.org/elderly-prison-population-nursing-eldercare/>.

⁶¹ "The various eligible public funding sources are administered through a number of different federal, state and local agencies, including the federal Department of Housing and Urban Development; state housing finance agencies, local housing authorities, and state Medicaid administering agencies. Each agency — indeed, each program — maintains different income eligibility standards, different sponsor eligibility requirements, different application timelines, and different levels of understanding of assisted living as a product." Scheutz, *Affordable*, 8.

will qualify for these programs based on their lower incomes. “Many older adults are subject to economic disparity, with 19 percent of older adults living in poverty, or near poverty. Older adult minorities have disproportionately been affected by poverty, especially [B]lack women, with 54 percent of [B]lack women who live alone falling below the official poverty index.”⁶² Over half of PLAHIV are living in poverty.⁶³ These disparities are also split along gender lines. “Older women and TGD [trans and gender diverse people] with HIV are more likely to be living in poverty (71% and 74%, respectively) than older men with HIV (57%; Cohen et al., 2019).”⁶⁴ Overall, this means that many PLAHIV are living on lower incomes, if not below the poverty line, and are in dire need of the limited available subsidies in order to have a place to live.

The use of criminal records as a basis for denial of public housing is the result of historic shifts in public housing policy and should be of concern to PLAHIV even if they have no criminal record.

Public Housing: Public housing is what most people think of when they think of subsidized housing. Public housing is a federally funded program with national rules and guidelines determined by Congress and/or HUD. The housing itself is owned and managed by local public housing authorities (PHAs) who act as the landlord. Although the overarching rules are decided on at the national level, each housing authority sets its own local rules and guidelines governing admission and tenancy. Tenants pay a portion of their income (capped at 30%) to the housing authority. Access to public housing is

different all over the country, with some areas having available units for qualified applicants, some having waitlists, and some have waitlists that have been closed for a substantial period of time. There is also public housing that is designated for older adults, which people may apply for based on their age. Designated public housing for older people serves those over the age of 62 whose income is less than 50% of the median income for their area.⁶⁵

Although different housing authorities use criminal records in different ways in making admissions determinations, a criminal record can be a hurdle if not an outright bar to a person’s ability to access subsidized housing. The only federally mandated bars to admission into public housing, or reasons for having one’s public housing terminated, are (1) being a lifetime enlistment on a sex offense registry, (2) having been convicted of manufacturing meth on public housing property, or (3) having within the previous three years been convicted of a drug offense.⁶⁶ However, local housing authorities have extensive latitude to create limits far in excess of the mandated ones, and most do. “[The Galveston Housing Authority], for example, has a policy requiring it to deny applicants if their criminal record includes ‘civil disobedience’ within the past ten years, meaning that a ten-year-old arrest record related to a political protest could result in a denial of housing.”⁶⁷ Furthermore, housing authority administrators, the ones in charge of making admissions determinations, can and do use the discretion they are given under the local housing authorities’ rules to deny rentals to people they could admit.

The use of criminal records as a basis for denial of public housing is the result of historic shifts in public housing policy and should be of concern

⁶² Jermaine Junius, “The Aging of HIV,” National Association of Social Workers, n.d., <https://www.socialworkers.org/LinkClick.aspx?fileticket=SMAGOUQJMj4%3D&portalid=0>.

⁶³ “Older Adult Clients: HRSA’s Ryan White HIV/AIDS Program, 2022,” HRSA, April 2024, <https://ryanwhite.hrsa.gov/sites/default/files/ryanwhite/resources/population-factsheet-older-adults.pdf>.

⁶⁴ Brennan-Ing et al., “Aging with HIV,” 6.

⁶⁵ Scheutz, *Affordable*, 38.

⁶⁶ Marie Claire Tran-Leung et al., “Frequently Asked Questions: HUD-Subsidized Housing for Older Adults with Criminal Records,” National Center on Law and Elder Rights, June 2023, https://pstrapiubntstorage.blob.core.windows.net/strapib/assets/HUD_Subsidized_FAQ_b3713c30d7.pdf.

⁶⁷ Schneider, “Homelessness Pipeline,” 437.

Nevada: A Housing Crisis for Aging People

Snapshot of Affordable Housing in Nevada

In Nevada, older adults and people living with disabilities make up 47% of all renter households within the Extremely Low Income (ELI) category, with incomes at or below 30% of their area median income.¹ With only 14 affordable and available rental units per 100 households at or below ELI level, there are simply not enough units to meet the need.² In Clark County, the state's most populous county, a recent count showed 10,000 older adults on waitlists for only nine facilities, with an average wait of two to three years.³ New developments are being built, but there will still not be enough units.

Nevada is one of the few states where more than *half* of its total population are people experiencing homelessness while unsheltered.⁴ An estimated 27 in every 10,000 people in Nevada are considered experiencing homelessness while sheltered.⁵ HUD defines “experiencing homelessness” as an individual (or a family) who lacks a fixed, regular, and adequate

nighttime residence, meaning an individual can have temporary shelter (i.e., be considered sheltered) but still be categorized as experiencing homelessness.

HUD does not have a blanket policy prohibiting all persons with criminal records from applying to HUD-funded housing but grants “broad discretion” for local public housing authorities to create their own policies when considering applicants with criminal backgrounds.⁶ Because of this, Nevada-based non-profit and faith-based organizations who receive HUD funding can require background checks from applicants and set their own admission policies.

In May 2024, HUD announced that \$4 million has been allocated for Nevada's Housing Opportunities for Persons with AIDS (HOPWA) program out of \$43 million in total funding grants, a \$1 million increase over the 2023 allocation.⁷ A 2022 study analyzing data from the Medical Monitoring Project and HOPWA found that 40.4% of PLHIV requiring aid in getting or staying housed did not receive it due to not being eligible or

¹ “Housing Needs by State: Nevada,” National Low Income Housing Coalition, 2024, <https://www.nlihc.org/housing-needs-by-state/nevada>.

² “The Gap: Nevada,” National Low Income Housing Coalition, 2024, <https://nlihc.org/gap/state/NV>.

³ “Solutions for Senior Affordable Housing on Their Way in Clark County,” Fox 5, March 21, 2024, <https://www.fox5vegas.com/Video/2024/03/21/solutions-senior-affordable-housing-their-way-clark-county/>.

⁴ Tanya de Sousa et al., *The 2023 Annual Homelessness Assessment Report (AHAR) to Congress*, HUD, 2023, <https://www.huduser.gov/portal/sites/default/files/pdf/2023-AHAR-Part-1.pdf>, 16. Point-in-time counts are one-night estimates of both sheltered and unsheltered populations experiencing homelessness, conducted by Continuums of Care nationwide annually in the last week of January.

⁵ Tanya de Sousa et al., *2023 Annual*, 10.

⁶ HUD Exchange, “FAQ ID 4078,” January 2022, <https://www.hudexchange.info/faqs/programs/housing-choice-voucher-program/eligibility-determination-and-denial-of-assistance/background-screening/are-applicants-with-felonies-banned-from-public-housing-or-any-other/>.

⁷ Kevin Sheridan, “More than \$43 Million in Housing Grants Coming to Nevada,” KOLO news, May 9, 2024, <https://www.kolotv.com/2024/05/09/more-than-43-million-housing-grants-coming-nevada/>; City of Las Vegas, *HUD Annual Action Plan FY 2023-2024*, May 2023, https://files.lasvegasnevada.gov/community-services/Grant%20Documents%202022-2023-2024/CLV-FY-2023-2024_HUD_Annual_Action_Plan.pdf.

to the service not meeting their needs.⁸ Hopefully, this additional money will help bridge that gap; however, based on the competition for housing, PLHIV who have a criminal record are likely to be deprioritized or stranded on waitlists.

Record Sealing: Process and Barriers

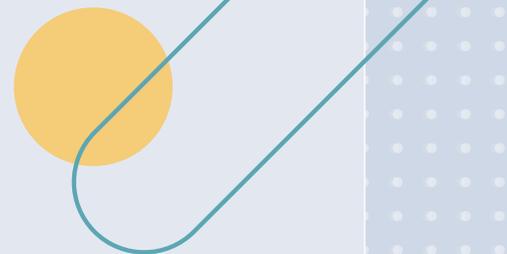
Record expungement is not an option for people in Nevada living with criminal records. Instead, individuals can file a petition to seal their criminal record.⁹ An order sealing records removes it from general information sources but they may still be used in certain circumstances such as an arrest for the same or a similar offense or during a new criminal action.¹⁰ Eligibility for record sealing depends on whether the entire sentence has been served, if the individual has remained conviction free, and if their conviction falls within the designated category. Different waiting periods are assigned for different sentences, e.g. five years for a Category B felony or two years for a misdemeanor.¹¹ Exceptions to record sealing eligibility include sex offense convictions. If the petition is denied, the petitioner may appeal.¹²

It can take from two to four months to complete the process of sealing a criminal record if all forms have been filled out and the petition filed accurately.¹³ Nevada

Legal Services (NLS) offers a step-by-step guide as well as assistance for sealing criminal records. If a PLHIV is enrolled in Ryan White Part B Programs and Services, NLS provides legal services for Housing, Public Benefits Denials, and Criminal Record Sealing, among others.¹⁴

Recent Research and Legislation

Having a criminal record is just one barrier for eligibility that PLHIV in Nevada face. Currently, there are no legislated protections against discrimination faced by people with criminal histories or people who were formerly incarcerated when applying for housing.¹⁵ In 2023, Senator Dina Neal introduced SB 143, making it unlawful to refuse to rent to an applicant due to arrest record, conviction record, or record of criminal history, but the bill failed.¹⁶ SB 143 is only the most recent in a line of proposed legislation attempting to create protections for those with criminal records.¹⁷



⁸ S. Dasgupta et al., (2022). Needs for Shelter or Housing Assistance among People with Diagnosed HIV by Jurisdiction: United States, 2015-2020, *AIDS* 37(3), 535-40, <https://doi.org/10.1097/qad.00000000000003460>.

⁹ Nev. Rev. Stat. Ann. § 179.245 (2023).

¹⁰ Nev. Rev. Stat. Ann. § 179.295(2) (2023); Nev. Rev. Stat. Ann. § 179.295(3) (2023).

¹¹ Nev. Rev. Stat. Ann. § 179.245(1)(b),(f).

¹² In *Matter of Tiffie*, 485 P.3d 1249 (Nev. 2021), the Nevada Supreme Court held that the petitioner was entitled to presumption in favor of record sealing and that the burden to prove lack of rehabilitation fell on the state.

¹³ Information on the Sealing of Nevada Criminal History Records,” [nv.gov](https://rccd.nv.gov/FeesForms/Criminal/Sealing_NV_Criminal_History_Records/), accessed July 29, 2024, https://rccd.nv.gov/FeesForms/Criminal/Sealing_NV_Criminal_History_Records/.

¹⁴ Ryan White Part B Programs and Services: Friday Health Plan Information,” DPBH, accessed July 29, 2024, https://dpbh.nv.gov/Programs/HIV-Ryan/Ryan_White_Part_B_-_Home/.

¹⁵ Michael Lyle, “Lawmaker Revives Effort to Remove Barrier Blocking Formerly Incarcerated from Housing,” *Nevada Current*, March 13, 2023, <https://nevadacurrent.com/2023/03/13/lawmaker-revives-effort-to-remove-barrier-blocking-formerly-incarcerated-from-housing/>.

¹⁶ Lyle, “Lawmaker Revives Effort to Remove Barrier.”

¹⁷ A 2021 version brought by Neal exempted single-family homes and was vetoed by then-Governor Steve Sisolak.

to PLAHIV even if they have no criminal record. When the public housing program was first developed in the early 20th century, it was seen as a way of providing housing during housing shortages to working- and lower-middle-class white families who could otherwise not find or afford it.⁶⁸ Over the next several decades, however, the percentage of Black people in public housing, especially in urban areas, dramatically increased.⁶⁹ Along with that, the perception of public housing began to shift to its being a charity — a privilege that should be accessible only to those who deserve it — and a place for “warehousing the poor.”⁷⁰ Tenant screening policies were used as a tool of regulation, providing another method to curb the rights of primarily Black tenants while white Americans were given access to mortgages with which they could purchase homes in the suburbs.⁷¹ In the 1990s, as part of his “tough-on-crime” agenda, President Clinton initiated a “one-strike rule,” meaning that a family could be evicted from public housing because of a single criminal conviction. This rule encompassed not only crimes committed by the head of the household (the primary leaseholder) but also crimes committed by their dependents while not on PHA property, or even by household guests while on public housing property.⁷²

One of the metrics by which local PHAs were evaluated was whether or not the manager

moved to evict anyone who fell under this “one-strike rule.”⁷³ Subsequently, due in large part to recognition of the equity concerns raised by the disparate impact on Black tenants from the administration of the one-strike rule, HUD rolled it back, eventually recommending (though not mandating) a more holistic, individualized review.⁷⁴ That said, the culture of eviction based on criminal record (and, similarly, denials based on the same) still exists within most local PHAs.

In the 1990s, as part of his “tough-on-crime” agenda, President Clinton initiated a “one-strike rule,” meaning that a family could be evicted from public housing because of a single criminal conviction.

The rules in local PHA Admission and Occupancy Plans give individual administrators the flexibility, without much oversight, to determine whom they believe deserve the privilege of tenancy, especially in underresourced urban areas.⁷⁵ It is this perception of housing as a privilege given to the deserving that should concern PLAHIV.⁷⁶ PLHIV are a protected class under the Americans with Disabilities Act (ADA). Nevertheless, considering

⁶⁸ Richard Rothstein, *The Color of Law: A Forgotten History of How Our Government Segregated America* (New York: W. W. Norton & Company, 2017), 17-18.

⁶⁹ Sara Miller, “Reconceptualizing Public Housing: Not as a Policed Site of Control, but as a System of Support,” *Geo. J. On. Poverty L. & Pol’y* 95, 28 (Fall 2020): 98-100.

⁷⁰ Rothstein, *The Color of Law*.

⁷¹ Michelle Y. Ewert, “Their Home is Not Their Castle: Subsidized Housing’s Intrusion into Family Privacy and Decisional Autonomy,” *N.C.L. Rev.* 99, 869 (May 2021), 875-81; Rothstein, *The Color of Law*, 64-67.

⁷² In this subsidized housing section, the author is focusing primarily on the impact of prior criminal records on admission to subsidized housing programs, as that seems to be the area that would impact PLAHIV the most. There is a similarly complicated process concerning termination from these programs due to criminal activity while someone is already residing in a property, or their ability to return to a public housing program after incarceration. Like admissions, the standards for termination weigh heavily against the tenants in practice, though in theory “holistic, individualized review” is often required. For example, the author has handled many cases in Philadelphia where the housing authority moved to evict a family upon the arrest of a tenant (not even just the head of household) prior to the criminal case being heard. He has also had to advocate for the early release of clients from incarceration so they did not risk losing their housing subsidy due to not residing in the property for 180 days.

⁷³ Miller, “Reconceptualizing Public Housing,” 103.

⁷⁴ Letter from Shaun Donovan, Sec’y of the Dep’t of Hous. and Urban Dev., to PHA Exec. Dirs. (June 17, 2011).

⁷⁵ Jesse Kropf, “Keeping ‘Them’ Out: Criminal Record Screening, Public Housing, and the Fight against Racial Caste,” *Geo. J. L. & Mod. Critical Race Persp.* 75, 4 (Spring 2012): 86.

⁷⁶ Thrasher, *Viral Underclass*. In his seminal text, *The Viral Underclass*, Professor Thrasher explains that now, 40 years into the HIV epidemic, with all of the scientific advancements in PReP and ART, the stigma against people who acquire HIV is such that they are deemed to have acted in a way as to “deserve” it.

the stigma that PLHIV bear, in conjunction with the evolution of housing being characterized as a privilege, it is not much of a stretch to be concerned that property managers might feel empowered, even encouraged (as long as their discrimination is not blatant enough to be caught), to deny housing to PLHIV.

The Section 8 Housing Choice Voucher

Program: Section 8 is a federal subsidy program administered by a local housing authority, where participants are given vouchers guaranteeing that the housing authority will pay a portion of their rent to private landlords who have agreed to participate in the program. To qualify for the Section 8 program, one must be below a certain income level, and similar to public housing, there can be long waitlists for a voucher. The Commission on Affordable Housing and Health

The Section 8 program was an effort to address the issue of de facto segregation caused by public housing that limited primarily Black tenants to certain areas.

estimates that 17% of voucher holders (255,000 out of 1.5 million) are older adults.⁷⁷ Once holders find a property and the landlord agrees to rent to them, the housing authority negotiates the rent and arranges the lease signing. Voucher holders are responsible for a portion of the rent that is no greater than a third of their income.

When discussing the Section 8 program's importance to older participants and its limitations for them, one should again take

note of the program's history. The Section 8 program began in 1974 as an effort to disperse large concentrations of lower-income tenants, caused in part by the towering buildings and the complexes that made up public housing at the time, and to allow lower-income tenants to move into "higher-opportunity" areas.⁷⁸ The program was also an effort to address the issue of de facto segregation caused by public housing that limited primarily Black tenants to certain areas.⁷⁹ Ostensibly, by not being restricted to housing owned and operated by the housing authority, Section 8 voucher holders could access housing throughout the city. That intended result has not manifested in many cities, however.⁸⁰ This is in large part due to the calculation of fair market rents made by HUD and the local housing authorities. HUD sets baseline fair market rents for areas according to zip codes, but housing authorities have the discretion to offer a certain percentage above that amount to landlords. Fair market rents act as a cap for what a housing authority will agree to pay for a property (and that includes the tenants' portion of the rent); once that cap is reached, a tenant has little ability to offer anything beyond it. These fair market rents have not remotely kept pace with the gentrification of, and therefore skyrocketing rents in, higher-opportunity areas. This means that an aging person might acquire a housing voucher but be unable either to remain in the area they have lived in their entire life or to relocate, because no landlord is willing to accept the amount of rent that the housing authority is willing to pay. Voucher holders are allowed to pay in excess of 30% of their income in rent,

⁷⁷ Scheutz, *Affordable*, 44.

⁷⁸ Eva Rosen, *The Voucher Promise: "Section 8" and the Fate of an American Neighborhood* (Princeton: Princeton University Press, 2020), 13-16; "Section 8 Housing Choice Vouchers: Overview," National Housing Law Project, July 25, 2022, <https://www.nhlp.org/wp-content/uploads/2018/03/3-NHLP-Voucher-Outline.pdf>.

⁷⁹ There are two types of segregation under the law, neither of which is permitted under the Fair Housing Act, which is addressed more in depth on page 16. The one people are more familiar with is de jure segregation, or purposeful segregation, the kind that was caused through redlining and restrictive covenants that permitted owners of houses to only sell to other white families — policies that specifically limited where Black people could and could not own property or rent. De facto segregation can be when segregation occurs as a presumably unintended result of a policy that is on its face racially neutral, or not motivated by race. For example, many cities were found to be guilty of de facto segregation based on the way that they constructed their sending districts for public schools; although the policies themselves did not mention race, the results were schools that entirely lacked in racial diversity. De facto segregation can be harder to "prove" than de jure segregation because race is not mentioned in the rule itself.

⁸⁰ "Fair Market Rents and Small Area Fair Market Rents (SAFMRs)," National Housing Law Project, accessed April 30, 2024, <https://www.nhlp.org/initiatives/housing-voucher-utilization/fair-market-rents/>.

up to 40%, but if they pay more, they risk losing their voucher. As of 2000, aging voucher holders have also been able to use their vouchers to pay a portion of assisted living costs. However, the cap on what they are able to contribute, combined with the low fair market rents set by local housing authorities, means that this change does not result in many voucher holders residing in assisted living facilities.⁸¹

The stigma of having a criminal record has an impact on admission into the Section 8 program similar to its impact on public housing admission. Although the local rules for Section 8 vouchers contained in the Housing Choice Voucher Administration Plan differ from public housing guidelines, in practice the policies that lead to admission denial due to criminal records are virtually the same. Section 8 voucher holders, however, face the additional hurdle of background checks performed by the private landlords from whom they want to rent. With their prior criminal record, they may have been able to obtain a voucher, but that same record may cause the landlord to reject them. Similarly, they face the effects of a prior incarceration on their credit scores, on their ability to show steady gainful employment, and on their practical ability to have the money that the landlord requires for security deposits and other move-in costs.⁸² In addition, older voucher holders living with HIV must deal with the same stigma and risk of discrimination (again, not permitted

under the ADA but occurring anyway) faced by unsubsidized private renters living with HIV if the landlord learns of their status.

Section 202 Supportive Housing for the Elderly Program:

The Section 202 Supportive Housing for the Elderly Program provides funding to support the development of housing for low-income older people, as well as rent subsidies that are known as “project-based vouchers.”⁸³ These housing developments must serve households with incomes of up to 50% of an area’s median income where at least one family member is age 62 or older.⁸⁴ The funding can be used for the housing portion of assisted living but not for the services component: “applicants must demonstrate commitments from other funding sources — such as Medicaid waivers and any other combination of sources — to cover these costs.”⁸⁵ These funds are distributed not to aging individuals but to nonprofit developers who commit to building housing for aging people that will be used by qualified applicants for at least 40 years.⁸⁶ This is an example of what is commonly known as “project-based” public housing. In the public housing and Section 8 voucher programs, the head of household “holds” the subsidy, and if the head of household moves, as long as they do so as required by their subsidy program, they retain their subsidy. In project-based housing, the subsidy is attached to the housing itself, meaning that if a person leaves the unit, they lose the

⁸¹ Scheutz, *Affordable*, 45. It is also important to note that both the Section 8 and public housing programs do have provisions by which someone who needs a live-in aide can request to have an additional room in their unit/on their voucher for that aide as a reasonable accommodation due to their health condition. The income of that live-in aide is not factored into the income used for rent calculations because that person is technically not supposed to be paying rent. In the case where the aide is a family member, this can cause a huge amount of consternation and confusion if the older person who is the head of household passes away. In situations where the aide is a family member AND on the lease, and therefore counted as part of the rent-paying household, the property/voucher can be inherited by that person. In a situation where they were not considered part of the rent-paying household, but just permitted to live in the property as a caregiver, they are not able to inherit the property/voucher, no matter what their family relationship was to the head of household, how long they lived there, or if they were at one point considered a member of the household (e.g., grown children who moved back in to care for the aging relative). This confusion can cause family members trying to deal with the death of a loved one suddenly being told by the local housing authority that they are being kicked out as well (which, depending on the jurisdiction, does not need to go through the formal eviction process).

⁸² For those reading this who have obtained or are in the process of obtaining a Section 8 voucher and are on a fixed income, although the housing authority will not help with the initial payment to the landlord (unless there are specific local programs of which the author is unaware) there are programs at many nonprofits and other government agencies, such as UESF for veterans, who do provide the money necessary.

⁸³ “Multifamily Housing Program Description: Section 202 Supportive,” U.S. Department of Housing and Urban Development (HUD), n.d., https://www.hud.gov/program_offices/housing/mfh/progdesc/eld202.

⁸⁴ Scheutz, *Affordable*, 46.

⁸⁵ Scheutz, *Affordable*, 46.

⁸⁶ HUD, “Section 202.”

subsidy. Section 202 Supportive Housing programs are the example of project-based housing given here because they are intended specifically for people over age 62, but there may be other forms of project-based housing that a PLAHIV could qualify for. The Section 202 rules regarding admissions and criminal records are typically identical to those governing Section 8 housing, but they can be different if, for example, the type of project-based housing is geared toward working with people who use drugs.

Housing Opportunities for Persons with AIDS (HOPWA): When most people think of subsidized housing for PLHIV, they are thinking of the Housing Opportunity for Persons with AIDS (HOPWA) program. This is another program operated by HUD. In the HOPWA program, 90% of funds are allocated to different jurisdictions based on a complex formula that considers such factors as number of HIV cases, poverty rates, and fair market rents.⁸⁷ But this formula has led to situations where resources are allocated in a way that leaves areas with high levels of unmet need, particularly in the South.⁸⁸ HOPWA funds are designated for low-income people (at or below 80% of the area’s median income) and provide housing assistance in a variety of ways that include acquiring and operating HOPWA housing, giving rental assistance, and providing services such as case management or daily living assistance.⁸⁹ How a qualifying jurisdiction chooses to use its funds is at its discretion. The HOPWA program does not require criminal background checks for recipients of the funds.⁹⁰

The Ryan White Act

The Ryan White HIV/AIDS Program is the largest federal program that provides grants to fund services for low-income PLHIV.⁹¹ Part A of the Ryan White Act provides funds that can be used for housing support. These funds are typically used for transitional housing and short-term housing support (assistance paying rent or a mortgage for a limited time), not for the permanent housing that HOPWA funds can be

The Ryan White HIV/AIDS Program is the largest federal program that provides grants to fund services and programs for low-income PLHIV.

used for. In June 2024 the Health Resources and Service Organization (HRSA), which administers Ryan White, clarified that Ryan White funds can be used to pay a PLHIV’s security deposit if there are policies in place to make sure that the money is refunded upon move out to the grantee organization, not to the PLHIV.⁹²

Low Income Tax Housing Credit

Similar to the Section 202 Supportive Housing programs, the owners of Low Income Tax Housing Credit (LITHC) properties receive benefits that help them with financing after committing to making a certain number of their units affordable for people with lower incomes.⁹³ For example, one ratio is 20% of affordable units at 50% of median income, meaning that this property must offer 20% of its units at the affordable rent rate (as set by the controlling agency) for someone who has up to 50% of the median income.⁹⁴ A single building may have

⁸⁷ Dasgupta et al., “Needs for Shelter,” 535.

⁸⁸ Dasgupta et al., “Needs for Shelter,” 536.

⁸⁹ “HOPWA Eligibility Requirements,” HUD Exchange, n.d., <https://www.hudexchange.info/programs/hopwa/hopwa-eligibility-requirements/>.

⁹⁰ “Housing Opportunities for Persons with AIDS (HOPWA) Program Guidelines and Policies,” Washington State Department of Commerce, August 17, 2016, <https://www.commerce.wa.gov/wp-content/uploads/2016/10/hau-hopwa-guidelines-2016.pdf>.

⁹¹ “Ryan White HIV/AIDS Program Legislation,” Health Resources & Services Administration, February 2022, <https://ryanwhite.hrsa.gov/about/legislation>.

⁹² Laura Cheever, *HAB Program Letter on Security Deposits*, HRSA Dear Colleagues Letter, June 26, 2024, <https://ryanwhite.hrsa.gov/sites/default/files/ryanwhite/grants/hrsa-hab-security-deposit-program-letter.pdf>.

⁹³ “Low Income Housing Tax Credit (LIHTC),” Philly Tenant, February 17, 2023, <https://phillytenant.org/lihtc/>.

⁹⁴ Scheutz, *Affordable*, 50.

multiple ratios, leading to a different percentage of units guaranteed to be affordable to people at different median incomes. Unfortunately, nothing in federal law prevents a person with a lower median income from being assigned a unit designated affordable for someone with a higher median income, even if more affordable units are also available in the building.⁹⁵ While LITHC properties create more affordable housing, they are not a subsidy that is paid to, or controlled by, the tenant. That said, many LITHC property developers combine this program with others, such as Section 202.⁹⁶

The LITHC is used to build housing that may be accessible to older residents but lacks the necessary supportive social services for its aging population.⁹⁷ The LITHC is the financing structure that has been used to develop LGBTQ+ housing for older people in major cities, including John C. Anderson in Philadelphia, The Pryde in Boston, and Stonewall House in New York City.⁹⁸ This is housing that is geared to providing a safe(r) community for LGBTQ+ people to live in and age, and properties subsidized through this program may be ones that PLAHIV are trying to qualify for.

PLAHIV should be aware that under the LITHC the rental cap that can be charged for an affordable unit is tied to the area's median income, not to the resident's income, unless there is an additional subsidy attached to a unit.⁹⁹ Therefore, a tenant's rent can be increased because of changes in the area, even if the person is on a fixed income that has not increased. Or, a tenant who qualified for an apartment because the calculation of

There are no federal restrictions on what kind of screening procedures a LITHC landlord can use, so people living and aging with HIV and who have criminal records face the same difficulties that they would on the private market.

their income includes their assets (such as money received from selling a home) can find themselves unable to afford rent after running through these assets. As a result, older tenants can be priced out of their affordable housing as time passes. There are no federal restrictions on what kind of screening procedures a LITHC landlord can use, so PLAHIV and who have criminal records face the same difficulties that they would on the private market.

⁹⁵ *An Advocate's Guide to Tenants' Rights in the Low-Income Housing Tax Credit Program*, National Housing Law Project, 2021, <https://www.nhlp.org/wp-content/uploads/LIHTC-2021.pdf>. For example, say a property owner agrees to make 20% of their units affordable to people at 50% of the median income and 20% of their units affordable to people at 40% of the median income (under the average income test). The developers would agree to these ratios due to the benefits that they receive — i.e., they do not come up with them, but these ratios also represent a floor, not a ceiling. States can impose different rules and qualifications for LITHC in their state, which may require a person to be assigned the more affordable unit if they qualify.

⁹⁶ Philly Tenant, "LIHTC."

⁹⁷ Scheutz, *Affordable*, 51.

⁹⁸ Donna Kimura, "Stonewall House Gives LGBTQ Seniors a Place to Call Home," *Housing Finance*, June 24, 2020, https://www.housingfinance.com/developments/stonewall-house-gives-lgbtq-seniors-a-place-to-call-home_o; "The Pryde: Our First Community," LGBTQ Senior Housing, n.d., <https://www.lgbtqseniorhousing.org/the-pryde>; "John C. Anderson Apartments: Case Study," Innova Services, May 5, 2021, <https://www.innovaservices.com/projects/john-anderson-apartments/>. Senior housing that is dedicated for LGBT people is being opened in many cities. These are typically small apartment complexes, which are funded in part using LITTC tax credits. Some units are therefore set aside for low-income LGBT folks.

⁹⁹ Philly Tenant, "LIHTC."

What Can People Living and Aging with Criminal Records Do?

There are clear steps for advocacy and protection that PLAHIV can take to try to mitigate the impact of prior criminal charges.

Thanks to a growing national awareness of the impact of collateral consequences on the formerly incarcerated, there is a movement focused on clearing people's prior records. Unfortunately, each state sets the rules governing how this is to be done, so no "one size fits all" policy exists. PLAHIV can take the steps necessary to clear their prior record, as much as that might be possible, so that it does not hinder them moving forward in such situations as applying for housing. Mechanisms for clearing records include:

Expungements/Redactions/Sealing: These are all ways of getting certain charges or entire cases off of one's record so that they are no longer discoverable through a background check.¹⁰⁰

Pardons: A "pardon" is the term for an official end to or limitation placed on the consequences that a person faces as a result of their conviction. This is not an exoneration, where someone is found to be not guilty of a crime that they had previously been convicted of. It is instead the result of an application made to the appropriate decision-making person or body requesting that someone be treated as though they had never been found guilty of *the crime that they admit having committed*. A pardon can be granted based on such criteria

as the person's conduct since the conviction, i.e., the ways that they have changed.

By clearing one's record, the collateral consequences of conviction can be minimized. For example, if someone took a misdemeanor plea deal conviction for "simple assault" to avoid the chance of an "aggravated assault" conviction — a felony — a redaction means that the fact that the person was ever charged with the felony will not show up on background checks. A landlord who may refuse to rent to someone who has an aggravated assault on their record (even if it was not pled to) may be willing to rent to someone who was only convicted of a misdemeanor. Pennsylvania, for example, allows individuals that have paid off all court costs and fines to get their entire record sealed after they turn 70.

Many states require that, as part of a person's sentence, the judge order a defendant to pay for their own prosecution in the form of court fines and costs. Defendants can also be ordered to make payments to the victims in the form of restitution. For aging PLHIV on fixed incomes, such court costs and fines can represent a form of debtors' prison; even if someone is able to get their probation terminated, they cannot get the charges off their record due to outstanding fines.

¹⁰⁰Even though all three ways of clearing one's record have similar impacts, they are not the same. More confusingly, different jurisdictions may use the same word to refer to different kinds of record-clearing options. For the purposes of this primer, the following definitions are being used. An expungement is the complete removal of something from one's record. It is typically only available on cases where prosecution was terminated, or the person was found not guilty after a hearing, although it can be available on a case-by-case, state-by-state, basis for certain diversion programs (alternatives to traditional prosecution). Redactions is where specific charge(s) are removed from one's record, although not the entire case. These apply, where available, when an individual was initially charged with an offense, but "pleaded down" to a different offense, or was found guilty of only certain offenses but not others. Sealing is available for people who have certain convictions on their records, though what convictions are eligible varies greatly. In this case, the record is "sealed," meaning that the public cannot access and it cannot be used on background checks, unless it is "unsealed" for some reason. It is important to note for noncitizens (including green card holders) that even if one's record has been expunged or sealed, it can potentially be used against a person for immigration purposes, and in fact the person may want to speak to an immigration attorney before clearing their record.

In many states, the clearing of someone's record does not happen automatically. That means that the individual must file a petition with the court requesting that their record be cleared. In the case of a pardon, the individual may have to gather a large amount of information to convince the decision maker in their state that they need to get the pardon to open up opportunities that they are currently barred from. What is required to be filed and how to file it depends on the state. Many public defender's offices will file the petitions for a person, at no cost and even if that person was not initially represented by the office, if at the time of reaching out to the offices the person is income eligible.

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Many programs now exist to help people clear their records, and a local public defender's office or legal aid group is likely to have information on how to contact them. For example, Community Legal Services (CLS) in Philadelphia provides direct representation for people in a wide range of civil areas, including Social Security and home ownership. CLS attorneys in the employment and housing (tenant defense) unit file petitions for expungement in criminal court because of the collateral consequences of these convictions. In general, local civil legal aid groups may either do the petitions themselves, even if criminal work is outside of their mandate, or may direct the individual to another, more appropriate, group. In addition, many local bar associations maintain lists of lawyers that

are willing to provide such services at no or low cost. Similarly, local LGBTQ+ centers, community centers, and HIV case management groups may have lists of attorneys who offer different forms of legal help and are considered LGBTQ+ competent and who are aware of the stigma and discrimination they face. The Ryan White Act also provides funding for legal services directed toward PLHIV, and has specifically made that available under certain circumstances to help cover the costs of clearing a PLHIV's record.¹⁰¹

If an older person cannot get their record cleared prior to applying for housing or for a program that does a background check, they should prepare to challenge a negative decision. As discussed earlier, most denials are discretionary, not mandated, meaning that they are open to challenge. For example, programs subsidized by HUD have highly regulated steps that landlords must go through when rejecting a prospective tenant, and rejection letters must include information about how to appeal. Typically, there is a limited time in which to file an appeal, and potentially specific documents and information that must be included. If someone is concerned about a rejection based on their criminal record, they must be sure to watch for these denial letters and not miss any deadlines for filing appeals. These deadlines are unforgiving — missing a deadline may mean giving up the opportunity to rightfully challenge a denial.

¹⁰¹ Laura Cheever, *HRSA-HAB Expungement Program Letter*, HRSA Dear Colleagues Letter, June 6, 2024, <https://ryanwhite.hrsa.gov/sites/default/files/ryanwhite/grants/hrsa-hab-expungement-program-letter.pdf>.

Clean Slate: Pennsylvania’s Reproducible Record Cleaning Project

Nearly 78 million people in the United States have an old criminal record.¹ People with old convictions—those who have “paid their debt to society” in the form of incarceration, probation, fines, and whatever other penalties they were assessed—find their ability to engage fully in society hampered by the collateral consequences attached to these convictions. Collateral consequences occur because of legislation, such as that which bars people from having a variety of professional licenses for certain convictions and because of stigma and bias, such as landlords who refuse to rent to tenants with convictions. Getting as much off of one’s prior record as possible can open new avenues of opportunity and truly give people with prior convictions the ability to fully participate in society. It is important to note, however, that even proponents of such reforms do not see them as the “be all, end all” of the work to end the harm of the criminal legal system, but they are a step forward.²

The impact of prior criminal convictions was a major impetus behind the passage of Pennsylvania’s Clean Slate laws in 2018, making it the first state to pass comprehensive Clean Slate legislation.³ “Clean Slate is a policy by which certain criminal records are automatically sealed

by the state without any action required by a petitioner.”⁴ Clean Slate laws target and “seal” from a general view not only arrests or cases for which one was found not guilty but also a range of criminal convictions (summaries, misdemeanors, even felonies) so that they cannot be found through a basic record search.⁵ With limited exceptions, sealed cases do not need to be reported to people such as potential employers. This sealing ends almost all collateral consequences caused by having a criminal record.⁶ In 2024, the latest amendments to the Clean Slate Act added felonies to the list of eligible convictions and shortened wait times for eligibility for many categories of offenses.⁷

The impact of prior criminal convictions was a major impetus behind the passage of Pennsylvania’s Clean Slate laws in 2018, making it the first state to pass comprehensive Clean Slate legislation.

Advocates for Clean Slate in Pennsylvania accomplished it with bipartisan support in a state that is often referred to as “purple,” with a

¹ *Toward Stability and Safety: Experiences of People with Old Criminal Records*, Alliance for Safety and Justice, August 2021, <https://allianceforsafetyandjustice.org/wp-content/uploads/2021/09/Convictions-Brief.pdf>.

² Community Legal Services et al., “Clean Slate: Advocacy Toolkit,” 2018, 1 <https://clsphila.org/wp-content/uploads/2019/05/Clean-Slate-Toolkit-10-2017.pdf>.

³ “Community Legal Services: Pioneers of Record Clearing,” CLS, <https://mycleanslatepa.com/cls-record-clearing/>.

⁴ CLS et al., “Clean Slate: Advocacy Toolkit.”

⁵ “Clean Slate Summary,” CLS, 2024, <https://mycleanslatepa.com/attorney-resources/>. Although most of the work of Clean Slate is done automatically through the Commonwealth’s database, there are some situations where people have to petition to get their records sealed.

⁶ Pa. St. Ann. 18 §§ 9121 and 9122 et seq. (2018).

⁷ “Clean Slate Summary,” CLS.

legislature made up of politicians ranging from Democrats from Philadelphia to Republicans from the middle districts. By the time the bill moved forward for a vote, more than half of the Senate were cosponsors (it eventually passed the Senate unanimously).⁸ Advocates accomplished this by using tools ranging from compelling client stories detailing the impact that criminal records had on them, to recruiting such cheerleaders as Malcolm Jenkins of the Philadelphia Eagles. They also generated a variety of talking points targeting different personalities and values, including:

1. Passage of Clean Slate will reduce the financial and workforce strain put on the courts through the current system of expungements
2. It will help the 30% of Pennsylvanians, who parent 50% of the Commonwealth's children, move on and provide for their families after successfully showing rehabilitation
3. It will improve public safety by providing people with criminal records hope of a fresh start, thereby reducing recidivism
4. It will increase tax revenues by cutting barriers between people with old criminal records and gainful employment
5. It will mean that the Commonwealth will spend less money operating the tools of incarceration and supervision
6. It will prevent homelessness caused by landlord background checks⁹

These arguments made by advocates were meaningful to different constituencies throughout the state and defied the

perception that conservative legislators are reluctant to pass laws that reform the criminal legal system. Furthermore, Pennsylvania advocates were able to

These arguments made by advocates were meaningful to different constituencies throughout the state and defied the perception that conservative legislators are reluctant to pass laws that reform the criminal legal system.

get sweeping legislation passed that made sealing automatic, resulting in limited oversight of the project once up and running. This not only means that sealing records is cheaper due to limited court involvement, but it also assures that treatment across counties and the judiciary is equivalent.

What was once a Pennsylvania project has now grown into a national movement.

For more information about the National Record Clearing Project visit <https://clsphila.org/national-record-clearing-project/>.

⁸ CLS et al., "Clean Slate: Advocacy Toolkit," 25.

⁹ CLS et al., "Clean Slate: Advocacy Toolkit," 23-35.

What Policy Areas Can People Living with HIV and Their Advocates Address?

As already pointed out, many PLAHIV have criminal records, and suffer the consequences of having such a record, because of laws that target or are hyperenforced against Black people, sex workers, LGBTQ+ people, and PLHIV. People can engage in many areas of legal advocacy to end or mitigate the impact of these laws. The suggestions here are not exhaustive; they are meant to alleviate the present negative impact of the system.¹⁰²

Across the nation, many PLHIV and their advocates are already engaged in the work to modernize laws criminalizing HIV. The Positive Justice Project at the Center for HIV Law and Policy (CHLP) has been and currently is a part of many coalitions working to make these changes. Since 1994, states either have repealed their laws criminalizing PLHIV or modified them to be more in line with what is known today about how HIV is acquired.¹⁰³ Although these campaigns have not always been able to achieve all of their goals, advocacy around HIV criminal law modernization is an important way to fight the stigma faced by PLHIV, as well as provide a potential avenue for people with prior convictions seeking to have their records expunged.

There are also groups working around the country advocating for different ways for people to get their records cleared. One approach is the movement focused on “sealing laws.” Historically, one could seek removal only for (1) charges for which there was no conviction, (2) cases for which there was no conviction, (3)

cases or charges off their record after completion of some sort of diversion or specialized program, or (4) if a pardon or exoneration was received. States with sealing laws have designated a specific list of convictions (normally, nonviolent misdemeanors) that, after certain terms are met (normally, a period of time without a conviction), can be “sealed” away, meaning that the public cannot see them and that they do not appear on a commercial background check (although the convictions can still be seen by governmental agencies such as the FBI). These laws can have huge benefits for people with decades-old criminal records, allowing them to qualify for certain programs. Another big issue being tackled nationally is the abolition of court costs and fines, at a minimum for lower-income folks who may be prevented by such costs from ever getting out of the system.

Across the nation, many people living with HIV and their advocates are already engaged in the work to modernize laws criminalizing HIV.

There are also movements, such as the Coalition to Abolish Death By Incarceration (CADBI) in Pennsylvania, geared toward assisting older people who have been incarcerated for decades under overly harsh

¹⁰² The suggestions here should be considered as part of a larger abolitionist framework however, not just as reforms that address such issues as “disproportionate” policing or alleviating the impact of convictions. “What is, so to speak, the object of abolition? Not so much the abolition of prisons but the abolition of a society that could have prisons, that could have slavery, that could have the wage, and therefore not abolition as the elimination of anything but abolition as the founding of a new society.” Fred Moten et al., “The University and the Undercommons: Seven Theses,” *Soc. Text* 22 (2004): 114. The reality is that people suffer daily due to the criminal legal system, and the steps that are necessary to alleviate that suffering through things like expungements are what are currently accessible to us. However, these bandaids must not be seen as the solutions themselves, because the only way to prevent future harm is to abolish the system that causes it in so many ways to so many people in its entirety.

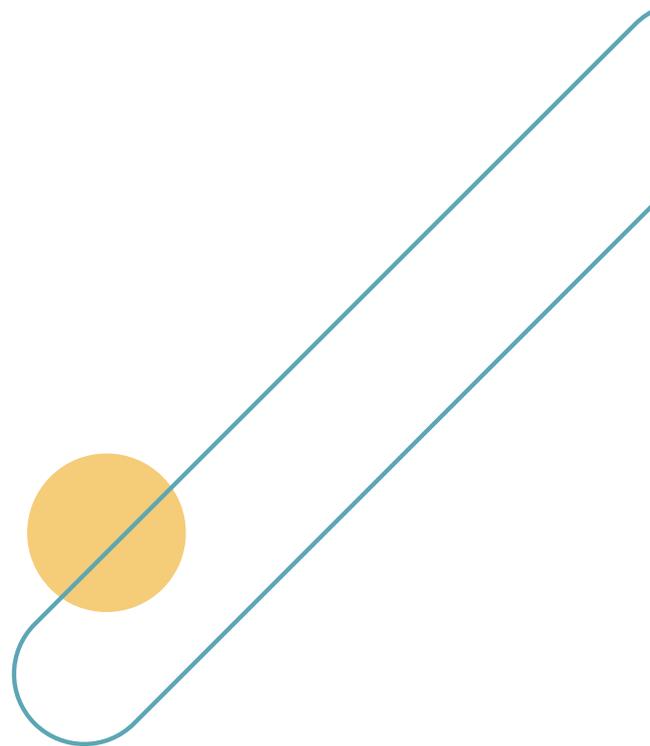
¹⁰³ CHLP, “Timeline.”

sentencing laws. These groups advocate for changes in the law to abolish life sentences for crimes. To prevent people from dying in prison, incarcerated people would be released before the end of their sentences and prior to when they would qualify for compassionate release because they are months from death. One huge victory achieved in 2012 through the work of advocates inside and outside the courtroom was the Supreme Court decision that found it unconstitutional to sentence juveniles to life sentences without parole. This decision led to the release of many “juvenile lifers” nationally, or at least gave many of them release dates and hope.

There are many avenues for work in support of people with criminal records generally that will also have a positive impact on PLAHIV.

Advocates can also be involved in the proposal of laws specifically aimed at alleviating the collateral consequences of criminal convictions. Fair Chance laws, for example, limit landlords’ ability to consider people’s prior criminal convictions when deciding whom to rent to. This helps address the discrimination and stigma that can make finding a place to live difficult, if not impossible, for someone with a record. Not only can these laws be passed on the state level, but they can sometimes be passed at the county or municipal level, and, consequently, they are a powerful area for local advocacy efforts. Although it is true that these laws do not necessarily end discrimination against people based on their criminal records, they can make it significantly more difficult for landlords and others to engage in discriminatory conduct.

There are many avenues for work in support of people with criminal records generally that will also have a positive impact on PLAHIV. This work stands as an important example of the principle that if advocacy is centered on the most marginalized groups, everyone will benefit.





“I’m only 54 but because I’ve been on HIV medicine for so long, they say it ages your organs. So my organs could be about 64. I feel my strength waning sometimes. I worry about not having enough food. I worry about not having a place to live at some point. What if the government is going to change their view on HIV and all of this goes away?

But the one thing I worry about the most — and this probably comes from taking care of my [late] wife — and that is not being able to take care of myself, because I don’t really have anybody I can rely on to help me.”

**STEPHANIE STUART
LONG-TERM SURVIVOR¹**

¹ Grace Birstengel, “We Weren’t Expected to Live This Long,” Next Avenue, February 21, 2020, <https://www.nextavenue.org/hiv-survivors/>.



Protections for Decision-Making Power

Even though HIV is a manageable condition, People Living and Aging with HIV (PLAHIV) can struggle with their physical and mental health in ways that affect their ability to meet the requirements of everyday life.² This is because they are living not only with HIV and its associated conditions but also with the physical and mental changes associated with aging generally. PLAHIV must overcome not just the limitations and failures of a U.S. healthcare system that is not designed to allow older people to age with dignity and in comfort (unless they can privately fund their needs) but also the specific barriers that they face as People Living with HIV (PLHIV).

What aging people consistently identify as important is the ability to retain as much control over their decision making as possible.

One area that can be a challenge for all aging people, and that holds unique concerns for PLAHIV, is retaining the power to make decisions about their lives and treatment.³ People living

with HIV have fought since the beginning of the AIDS epidemic, epitomized by the drafting of the Denver Principles, to make sure that their needs and desires are central to any decision that involves them as individuals and PLHIV as a community.⁴ But PLAHIV must now also confront ageism. A typically ageist view of older people is that they are less able than younger people to make their own decisions.⁵

Furthermore, aging peoples' decision-making power is constricted by the options available to them by the systems in which they engage. For example, having a lower income can limit the range of choices that PLAHIV have, because of their limited spending power and how they must conform to meet the eligibility requirements of government assistance programs. Nevertheless, what aging people consistently identify as important to them is being able to retain as much control over their decision making as possible, even when that means authorizing others to make their wishes known if they are unable to speak for themselves.

² "Living With HIV," CDC, accessed July 30, 2024, <https://www.cdc.gov/hiv/living-with/>.

³ Decision-making power used here refers to having not only the ability but the legal authority to dictate how one wishes to address issues in one's life, from how to spend one's money to whether one wants medical care.

⁴ "Why the HIV Epidemic Is Not Over," World Health Organization, accessed May 7, 2024, <https://www.who.int/news-room/spotlight/why-the-hiv-epidemic-is-not-over>; "The Denver Principles (1983)," UNAIDS, accessed May 21, 2024, https://data.unaids.org/pub/externaldocument/2007/gipa1983denverprinciples_en.pdf.

⁵ Health Resources and Services Administration (HRSA) HIV/AIDS Bureau (HAB), "Addressing the Health Care and Social Support Needs of People Aging with HIV: Technical Expert Panel Executive Summary," Ryan White HIV/AIDS Program, November 2020, <https://ryanwhite.hrsa.gov/sites/default/files/ryanwhite/resources/hrsa-aging-tep-summary.pdf>.

What are Common Barriers to Retaining Decision-Making Power?

Many if not most of the barriers faced by PLAHIV are similar to those faced by all people who are aging in the United States. For example, to make one's end-of-life decisions not only known but binding requires a variety of legal documents to be in place. Yet people with lower incomes may have difficulty finding and working with an attorney who can help them with this process. Moreover, PLAHIV have unique considerations that make them particularly vulnerable to losing control over their decisions.

The ways that PLAHIV physically age can complicate their ability to retain decision-making power where the systems are not set up to address the needs of an aging population before age 65. The bodies and organs of PLAHIV are typically "older" than those of other people of the same age.⁶ After age 50, PLAHIV may have the same physical conditions as someone a decade older.⁷ However, services geared toward "older" adults typically require a person to be chronologically older than 50 to access them.⁸ In addition, PLAHIV may also live with a variety of comorbid conditions because of complications associated with the use of Anti-Retroviral Therapy (ART). These conditions include cardiovascular disease, liver disease, diabetes, and cancer.⁹ The variety of comorbidities can make using the healthcare system difficult, if not impossible, and forces PLAHIV to navigate interlocking networks of private and/or state medical plans — all dedicated, it sometimes seems, to the production of red tape.

The law is not well equipped to handle mental or physical conditions that are neither static nor continuously deteriorating. Living and aging with HIV, "[C]an have adverse effects on the brain, making older adults with HIV more susceptible to negative mental health outcomes such as depression, dementia, and Alzheimer's disease."¹⁰ For example, someone who becomes depressed may have such difficulty taking care of life's necessities that they need assistance in making certain decisions, but after receiving treatment for their depression they may no

The guardianship system is not set up to deal with the sometimes episodic medical conditions, both physical and mental, associated with living and aging with HIV.

longer need that assistance. If a guardian — a legally appointed substitute decision maker — had been appointed during the time they did need help, they might now have to fight to regain control over their life. Moreover, guardians may fight to keep control, some for altruistic (if paternalistic) reasons and some incentivized by the fact that being a guardian can be lucrative (some people work as professional guardians).¹¹ The guardianship system is not set up to deal with the sometimes episodic medical conditions, both physical and mental, associated with living and aging with HIV.

⁶ Mei Li et al., "Preference for Care Models Among Older People Living with HIV: Cross-sectional Study," *BMC Public Health* 23, no. 1 (October 18, 2023), <https://doi.org/10.1186/s12889-023-16941-9>.

⁷ Jacqueline McMillan et al., "Managing HIV Infection in Patients Older Than 50 Years," *Canadian Medical Association Journal* 190, no. 42 (October 21, 2018): E1253–58, <https://doi.org/10.1503/cmaj.171409>.

⁸ "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)." HRSA, "Addressing Health Care."

⁹ Sean Cahill, Ph.D. et al., "Growing Older with HIV/AIDS: New Public Health Challenges," *American Journal of Public Health* 103, no. 3 (March 2013): 8, <https://ajph.aphapublications.org/doi/full/10.2105/AJPH.2012.301161>.

¹⁰ Cahill, "Growing Older," 8.

¹¹ "Supported Decision Making & the Problems of Guardianship," American Civil Liberties Union, accessed February 16, 2022, <https://www.aclu.org/issues/disability-rights/integration-and-autonomy-people-disabilities/supported-decision-making>.

Although many PLAHIV have robust “chosen families” and support networks, the majority still may not have anyone to rely on to step in as a caregiver. “[C]hosen family networks are at a significant disadvantage when it comes to caregiving in later life because they tend to be comprised of individuals who are in the same age cohort and aging policies typically assume a multi-generational support system.”¹² Chosen families are an important part of LGBTQ+ culture, providing familial love and support to those who may be estranged from or rejected by their birth family.¹³ Even those within the LGBTQ+ community who remain connected to their biological families often have people in their lives whom they define as their chosen family, with their connections to these individuals going deeper than friendship. The Second Annual State of Aging with HIV National Survey found that only 30% of PLAHIV have a spouse or domestic partner on whom they can rely.¹⁴ For PLAHIV who have maintained a strong relationship with their birth family, as well as for those who rely on a chosen family, their support network may be willing to assist but unable

to do so because of geography (e.g., living in another state) or because they cannot get time off from work.¹⁵ “Life events such as retirement, illness, relocation and death of family and loved ones can result in shrinking social networks.”¹⁶ Caregiving work is undersubsidized and underresourced, with family caregivers providing the equivalent of hundreds of billions of dollars of free care annually to their loved ones.¹⁷ Black people older than 50, when compared to the rest of the aging population, are more likely to receive care from a relative or a close friend than from formal, potentially costly, support systems.¹⁸ Providing free caregiving support on top of a paid job is exhausting for family members and may be impossible depending on the circumstances, leading PLAHIV to scramble to fill the gaps.

Although today’s laws on decision making more often take into account chosen families, there are still large legal hurdles to overcome.¹⁹ In the absence of formal advanced planning documents, such as a power of attorney, many states default to using members of a person’s biological family as automatic decision makers.²⁰

¹² Nancy J. Knauer, “LGBT Issues and Adult Guardianship: A Comparative Perspective,” in *Comparative Perspectives on Guardianship*, ed. Kim Dayton (Durham: Carolina Academic Press, 2014)(accessed electronically) https://papers.ssrn.com/sol3/papers.cfm?abstract_id=2147988.

¹³ Nancy J. Knauer, “LGBT Older Adults, Chosen Family, and Caregiving,” *Journal of Law and Religion* 31, no. 2 (July 2016): 157-58, <https://www.jstor.org/stable/26336669>.

¹⁴ HealthHIV, Second Annual State of Aging with HIV National Survey, 2021, 20, https://healthhiv.org/wp-content/uploads/2021/07/HealthHIV_Second_Annual_State_of_Aging_with_HIV.pdf.

¹⁵ Maureen E. Lyon et al., “FAMILY-CENTERED (FACE) Advance Care Planning among African-American and Non-African-American Adults Living with HIV in Washington, DC: A Randomized Controlled Trial to Increase Documentation and Health Equity,” *Journal of Pain and Symptom Management* 57, no. 3 (March 1, 2019): 613, <https://doi.org/10.1016/j.jpainsymman.2018.11.014>.

¹⁶ Stephen E. Karpiak et al., Research on Older Adults with HIV, AIDS Community Research Initiative of America, 2006, https://www.health.ny.gov/diseases/aids/providers/conferences/docs/roah_final_report.pdf.

¹⁷ The undersubsidization of long-term caregivers is “good business sense” for government officials. One study found that in 2021 caregivers in California for adults with Alzheimer’s and related dementias (not limited to those also living with HIV) provided close to 19 BILLION DOLLARS in unpaid care. Lisa Nerenberg et al., *Reinforcing California’s Elder Justice Infrastructure: Committing to Equity and Inclusion*, Elder Justice California, 2023, 54, https://www.elderjusticecal.org/uploads/1/0/1/7/101741090/cejc_blueprint2023_web.pdf.

¹⁸ “Whereas 45 percent of caregivers for all Americans age 50+ are the sole providers of care and are unpaid, that percentage jumps to 52 percent for Older African Americans. In the vast majority of unpaid assistance, the caregiver is a relative or close friend.” National Caucus and Center on Black Aging, Inc., *Black and Aging in America*, 2020, https://ncba-aging.org/wp-content/uploads/2023/01/FINAL-NCBA_Black_Aging_America_Digital_web47.pdf.

¹⁹ “We define ‘family caregiver’ to include the following subsets: adult family members or other individuals who are caring for an older individual, adult family members or other individuals who are caring for an individual of any age with Alzheimer’s disease or a related disorder with neurological and organic brain dysfunction, and ‘older relative caregivers’ (defined below). With this inclusive approach to defining ‘family caregiver,’ we include those populations specified in the National Family Caregiver Support Program, as set forth in Title III, part E of the Act. For example, this includes unmarried partners, friends, or neighbors caring for an older adult.” Administration for Community Living, “Older Americans Act: Grants to State and Community Programs on Aging,” Federal Register, February 14, 2024, <https://public-inspection.federalregister.gov/2024-01913.pdf>.

²⁰ Justice in Aging et al., *LGBT Older Adults in Long-Term Care Facilities: Stories from the Field*, June 2015, 27, https://www.justiceinaging.org/wp-content/uploads/2011/04/RE_LGBT-Stories-from-the-Field.pdf.

An Aggressive Medicaid Estate Recovery Program in Ohio

PLAHIV who rely on Medicaid to cover the costs for all or part of their care risk having their state government go after their “estate” in an effort to recoup costs associated with their care. This is due to a 1993 requirement passed by the federal government that every state have an estate recovery program for Medicaid dollars. Aside from the requirement that each state have a program that reaches assets that go through probate and a few protections for inheritors, the federal government left it up to each state to determine how aggressive their recovery program would be.¹

Ohio has one of the most aggressive programs in the country, recovering more than \$87 million in 2022.

The purpose of the Medicaid estate recovery program is ostensibly to force people who were able to retain assets

to pay their “fair share” toward their healthcare.² The recovery program does not exempt assets that are exempted for the purpose of qualifying for Medicaid. Practically speaking, wealthier people who can afford lawyers are more likely to retain more of their assets while qualifying for Medicaid whereas lower-income people are not (or do not have assets to begin with).³ The requirement limits the ability of lower-income families to create generational wealth.⁴ The Federal Medicaid and CHIP Payment and Access Commission found that the policies likely placed particular burdens on “people of color.”⁵

Ohio has one of the most aggressive recovery programs in the country, reclaiming more than \$87 million in 2022.⁶ This program goes well beyond basic federal requirements and includes all assets whether or not they must go through probate to be inherited.⁷ The program directs the Ohio attorney general (AG) to recover the cost of care provided to people who are either permanently institutionalized (regardless

¹ Katie L. Summers, “Medicaid Estate Recovery: To Expand, or Not to Expand, That Is the Question,” *Penn State Law Review* 18 (Fall 2013): 468. This program was made required after the passage of the Omnibus Budget Reconciliation Act (OBRA).

² Alexandra Smith, “Widening the Gap between Rich and Poor: Issues and Recommendations for the Implementation of Michigan’s Medical Estate Recovery Law,” *U. Detroit Mercy Law Review* 90 (Fall 2021): 149.

³ Nick Blizzard, “Options, Resources Available to Help Avoid Medicaid Taking Your Assets,” *Dayton Daily News*, July 28, 2023, <https://www.daytondailynews.com/local/options-resources-available-to-help-avoid-medicaid-taking-your-assets/GWDPDDUTAVFCFAMRG4TRGYNHFM/>; Summers, “Medicaid Estate,” 466.

⁴ See *in part* Summers, “Medicaid Estate.”

⁵ Chapter 3: Medicaid Estate Recovery: Improving Policy and Promoting Equity, MACPAC, 2021, <https://www.macpac.gov/wp-content/uploads/2021/03/Chapter-3-Medicaid-Estate-Recovery-Improving-Policy-and-Promoting-Equity.pdf>.

⁶ Nick Blizzard, “‘I’m Going to Be Homeless’: Ohio Medicaid Collects \$87.5M from Families After Loved Ones’ Death,” *Dayton Daily News*, July 29, 2023, <https://www.daytondailynews.com/local/im-going-to-be-homeless-ohio-medicaid-collects-875m-from-families-after-loved-ones-death/SYA3Y5TAEVE4NLNBWKNDOKIMSM/>.

⁷ Ohio Admin. Code § 5160:1-2-07 (2018).

of age) or have accrued benefits after turning 55.⁸ This recovery cannot typically be stopped in its entirety, only delayed under limited circumstances.⁹ If those guidelines are met, estate recovery can proceed even if it leads to the sale of the family home while family members still reside in it.¹⁰ Families can apply for an undue hardship waiver that will be granted on a case-by-case basis under compelling circumstances – and likely will only lead to a delay while the hardship exists or a modification of the amount sought.¹¹

Even with these aggressive tactics, Ohio’s program only recoups less than one percent of annual Medicaid expenditures, making the overall benefit of the program questionable.

The aggressive collection techniques employed by the program regularly result in grieving family members receiving letters from the state Medicaid department informing them that they owe tens of thousands of dollars

from the estate.¹² Even with these aggressive tactics, Ohio’s program only recoups less than one percent of annual Medicaid expenditures, making the overall benefit of the program questionable.¹³ Because Medicaid is heavily used by PLHIV nationally to supplement other forms of support, the negative impact of programs like this on families, even if they are less aggressive, is likely to be similarly profound with little or no benefit to the state.¹⁴

⁸ Ohio Admin. Code § 5160:1-2-07(C) (2018).

⁹ Estate recovery can only be paused until (1) the death of the surviving spouse; or (2) all surviving children are over the age of 21; or (3) all children who are blind or “totally” disabled have died. Ohio Admin. Code § 5160:1-2-07(D) (2018).

¹⁰ Ohio Admin. Code § 5160:1-2-07(D)(3) (2018). This is barring limited exceptions for certain siblings/adult children living in the home.

¹¹ “Medicaid Estate Recovery,” Pro Seniors, <https://www.proseniors.org/wp-content/uploads/2023/02/MER-2024.pdf>.

¹² Blizzard, “Homeless.”

¹³ Samantha Wildrow et al., “Ohio’s Aggressive Medicaid Estate Recovery Efforts Recoup Less Than 1% of Costs,” *Dayton Daily News*, October 2, 2023, <https://www.daytondailynews.com/ohio/ohios-aggressive-medicaid-estate-recovery-efforts-recoup-less-than-1-of-costs/ICSTCC3BL5BWTHQRFSF7EWXVAI/>.

¹⁴ “Medicaid accounted for 45% of all federal HIV spending in FY22 and it is the largest source of public spending for HIV care in the U.S. In FY22, the federal government spent an estimated \$13 billion on Medicaid services for people with HIV. Additionally, state Medicaid spending totaled an estimated \$5.4 billion in FY22.”; Lindsey Dawson et al., “Medicaid and People with HIV,” KFF, March 27, 2023, <https://www.kff.org/hiv/issue-brief/medicaid-and-people-with-hiv/>.

But many PLAHIV may be estranged from their biological family because HIV is still a stigmatized condition or because they were rejected for other reasons, including their gender identity or sexuality.²¹ Therefore, PLAHIV may not want their biological family members to automatically become their decision makers.

PUBLIC BENEFITS

A lack of financial resources can also constrict the decision-making ability of PLAHIV. Fifty-seven percent of PLAHIV are living below the poverty line, with the percentage rocketing up to between 71 and 74 percent for women and for transgender and gender-non-conforming people.²² Having a lower income in a world that dehumanizes people who live in poverty affects the validity ascribed to their decision making, especially regarding how they prioritize using the funds they do have. In her article “How Poverty and Aging Masquerade as Incapacity for Low-Income Older Adults,” Nicole Shannon, J.D., writes:

Older adults living in poverty must contend with the dual prejudices of society. One result of ageism is assuming that older adults are incapable of handling their own affairs and need to be stripped of independence and autonomy for their own protection. Likewise, society places harsh value judgments on people living in poverty and how they spend their money. These prejudices combine to treat low-income older adults as incapable of handling their own affairs, and morally incorrect in their attempts to do so.²³

Lower-income people rely on various government benefits and supports to meet their daily needs. Each of these programs comes with different requirements that lower-income individuals must meet to qualify, with limitations on how the benefits can be used that reflect prejudices against lower-income people and with biased ways of identifying and regulating “abuse.” One example of a program that restricts its recipients’ freedom to make decisions is the Supplemental Nutritional Assistance Program (SNAP). SNAP is used by 40% to 50% of women and people of trans experience living with HIV, and it permits recipients to buy items on a list of approved purchases but excludes some premade food, such as sandwiches or hot meals from a deli that many older people rely on.²⁴ Other benefit programs similarly place paternalistic limits on users’ decisions ranging from the important to the mundane, thereby limiting the options available to PLAHIV who need the programs’ support.

Having a lower income not only affects people’s ability to save for retirement or to have an estate plan but it also significantly restricts those individuals’ access to the full range of options available to higher-income aging people.

²¹ Justice in Aging et al., *Stories from the Field*, 27.

²² Mark Brennan-Ing et al., “Aging with HIV: Health Policy and Advocacy Priorities,” *Health Education & Behavior* 48, no. 1 (January 7, 2021): 5–8, <https://doi.org/10.1177/1090198120984368>; Paul Denning et al., “Communities in Crisis: Is There a Generalized HIV Epidemic in Impoverished Urban Areas of the United States?,” July 2010, https://www.law.berkeley.edu/files/DenningandDiNenno_XXXX-1.pdf. Poverty is a social determinant of health that makes people more vulnerable to acquiring HIV. In the United States, people who live in “poverty areas” (where at least 20% of the population have income levels below the poverty line) are significantly more vulnerable to acquiring HIV, with Black people being disproportionately likely to live in a designated “poverty area.”

²³ Nicole Shannon, J.D., “How Poverty and Aging Masquerade as Incapacity for Low-Income Older Adults,” *Bifocal* 45, no. 4 (March 28, 2024): 115, https://www.americanbar.org/groups/law_aging/publications/bifocal/vol45/vol44issue5/povertymasqueradingasincapacity/.

²⁴ Drew Desilver, “What the Data Says About Food Stamps in the U.S.,” Pew Research Center, July 19, 2023, <https://www.pewresearch.org/short-reads/2023/07/19/what-the-data-says-about-food-stamps-in-the-u-s/>; Heather Hahn et al., “Poverty Results from Structural Barriers, Not Personal Choices. Safety Net Programs Should Reflect That Fact,” Urban Institute, February 16, 2021, <https://www.urban.org/urban-wire/poverty-results-structural-barriers-not-personal-choices-safety-net-programs-should-reflect-fact>; US PLHIV Caucus, “Demanding Better: An HIV Federal Policy Agenda by People Living with HIV,” last accessed May 11, 2024, <https://www.pwn-usa.org/wp-content/uploads/2021/07/Networks-Policy-Agenda-FINAL.pdf>.

Having a lower income influences people's ability to save and plan for their future. The Third Annual State of Aging with HIV National Survey found that "[h]alf of respondents had no financial retirement plan and 4 in 5 had not saved enough for long-term care or supportive home care."²⁵ Having a lower income not only affects people's ability to save for retirement or to have an estate plan but it also significantly restricts those individuals' access to the full range of options available to higher-income aging people. This limitation is the direct result of the restrictions that government programs that provide or subsidize income or healthcare place on the people who use them. These restrictions not only constrain a person's ability to make decisions on their behalf but they also may limit the decisions that the person's caretakers or medical providers can make. In one example, people on Medicare often find themselves in a nursing home well before they need that level of care because of the rules against using Medicare to pay for assisted living.

This result assumes a PLAHIV can even get the benefits that they otherwise qualify for.²⁶ In the name of "deterring fraud," different government benefit programs are subject to interlocking county, state, and federal guidelines and rules that often place roadblocks in front of those trying to access benefits.²⁷ Professor Elizabeth F. Emens,

who has studied the impact of "disability admin," comprising benefits admin and medical admin, on people's ability to access government benefits, defines "benefits admin" as:

[T]he office-type work involved in applying for, justifying, renewing, and, where necessary, legally contesting government benefits. This includes benefits from federal, state, and local governments — both those that supplement income because of disability and those that provide healthcare or other services (like in-home aides or physical equipment such as wheelchairs or service animals) in response to disability, as well as those responding to particular experiences, such as veterans' benefits.²⁸

Some benefits admin may be impossible to navigate without help.²⁹ This is in addition to medical admin, which includes all of the admin that goes along with acquiring and paying for treatment for any medical condition.³⁰ One view of these bureaucratic barriers to obtaining services is that the government, in the name of limiting access to benefits to the "most deserving," has put into practice the technique of "ration[ing] by hassle" used by the private sector.³¹ For low-income PLAHIV the stakes are high and the repercussions huge if they fail to properly complete their disability admin,

²⁵ HealthHIV, Third Annual State of Aging with HIV National Survey, 2024, <https://healthhiv.org/stateof/agingwithhiv/?eType=EmailBroadcastContent&eld=883056c6-e9af-47dc-a653-022e1f4fb9fc>.

²⁶ "For a person who lacks privilege and resources, trying to navigate a disability benefits regime — for oneself or a loved one — may be at best overwhelming and at worst insurmountable. Legal assistance may be necessary but also challenging to secure and to weather." Elizabeth F. Emens, "Disability Admin: The Invisible Costs of Being Disabled," *Minn. L. Rev.* 105 (May 2021): 2346, <https://scholarship.law.umn.edu/mlr/3314/>.

²⁷ The history of American benefit programs is beyond the scope of this primer. It is important to note, however, that the ways in which these programs were viewed and policed changed drastically after Black people were allowed to utilize them, especially when they were viewed (incorrectly) as the primary users. These histories can be found in books such as Ben Austen, *High-Risers: Cabrini-Green and the Fate of American Public Housing* (New York: Harper Books, 2018); Richard Rothstein, *The Color of Law: A Forgotten History of How Our Government Segregated America* (New York: Liveright Publishing Corporation, 2018); Josh Levin, *The Queen: The Forgotten Life Behind an American Myth* (New York: Little Brown and Company, 2019).

²⁸ Emens, "Disability Admin," 2344.

²⁹ For example, in Philadelphia, attorneys who work with people applying for SSDI typically call the local Social Security office in the morning when they know they need to speak to someone about a case. They then remain on hold for the next several hours while they do other work waiting for their call to be answered. The ability to sit on hold all day to get a simple question answered is not something that many people actually have the time to do (unless they are being paid for it). Based on anecdotal information relayed to the author.

³⁰ Emens, "Disability Admin," 2342.

³¹ "The term 'rationing by hassle' emerges from the insurance industry, so private entities also impose hassle costs. (If in doubt, consider why companies offer rebates rather than just discounting the price of a sale.) But while no private insurer admits to rationing by hassle, rationing public benefits through administrative hassle is sometimes explicitly embraced as sound public policy." Emens, "Disability Admin," 2349.

whatever the justification for imposing it is.³² “Unfortunately, the person least able to navigate a complicated bureaucratic apparatus may be the person who most needs the benefit.”³³ This observation is particularly salient when someone is improperly denied and must take corrective steps by the proper deadlines to appeal their case, especially considering the proportion of cases that are first denied and later granted.³⁴

What programs people qualify for and can use to support themselves as they age can also be affected by their medical history and its impact on their ability to work. For example, the U.S. Social Security Administration (SSA) offers several types of payments that PLAHIV may apply and qualify for over time or, in some cases, simultaneously. These types of payments are as follows:

Social Security Retirement Benefits

Social Security retirement benefits are what people typically mean when they refer to Social Security. It is a monthly payment that people can begin collecting after age 62 if they have earned at least 40 credits. An individual can earn a maximum of four credits per year, and as of 2024, one credit for every \$1,730 earned and reported to the government.³⁵ It is funded through withdrawals from a person’s paycheck by the government when that person is working. The amount of money paid to someone once they apply is calculated using their highest salaries from 35 years of their work history.³⁶ A “\$0” is used for any year that the individual did

not work, reducing their monthly payment.³⁷ The amount paid is also impacted by how long a person is able to wait before applying, rewarding that person with higher payments the closer they get to age 70.³⁸

Social Security Disability Insurance (SSDI)

To be eligible for SSDI, a person needs to have a qualifying disability and to have worked long enough to earn a certain number of credits before becoming unable to work because of that disability.³⁹ For example, a PLAHIV who applies for SSDI when they are age 50 needs to have earned 28 credits to qualify.⁴⁰ A disability is “the inability to do any substantial gainful activity by reason of any medically determinable physical or mental impairment that can be expected to result in death or has lasted or can be expected to last for a continuous period of not less than 12 months.”⁴¹ PLAHIV can qualify for SSDI if they have a qualifying disability other than HIV or if they have “either a serious HIV-related condition, a qualifying CD4 count [under 50], repeated hospitalizations, or ... ‘repeated manifestations of HIV.’”⁴² Whether someone has a qualifying disability is periodically reviewed based on how long the disability is supposed to last.⁴³

Supplemental Security Income (SSI)

SSI is a needs-based program available to low-income individuals who either (a) are under the age of 65 but have a physical or mental condition that “seriously limits their functioning” (i.e., a

³² Emens, “Disability Admin,” 2336.

³³ Emens, “Disability Admin,” 2349.

³⁴ “What Is the Approval Rate for Social Security Disability Benefits?” USAFacts, December 12, 2023, <https://usafacts.org/data-projects/disability-benefit-process>.

³⁵ “How You Earn Credits,” Social Security Administration, 2024, <https://www.ssa.gov/pubs/EN-05-10072.pdf>. Many people who earn money “off the books” as part of the informal or gray economy will therefore not be able to apply all of those years of working to Social Security, and thus be forced to retire on Supplemental Security Income (SSI).

³⁶ Kimberly Blanton, “Your Social Security: 35 Years of Work,” Center for Retirement Research, October 20, 2016, <https://crr.bc.edu/your-social-security-35-years-of-work/>.

³⁷ “Benefits Planner: Retirement: The Age You Start Receiving Benefits and the Age You Stop Working,” last accessed May 11, 2024, <https://www.ssa.gov/benefits/retirement/planner/stopwork.html#:~:text=The%20age%20you%20stop%20working%20can%20affect%20the%20amount%20of,age%20you%20start%20receiving%20benefits>

³⁸ “Benefits Planner: Retirement,” Social Security Administration, <https://www.ssa.gov/prepare/plan-retirement>.

³⁹ Please note that the definition of “disability” used for SSDI is different from the one discussed in section 1 under the ADA.

⁴⁰ “How You Earn Credits.”

⁴¹ 20 C.F.R. § 404.1505.

⁴² “Social Security Changes HIV Disability Rules and Institutes Periodic Reviews of HIV Claims,” California HIV/AIDS Policy Research Centers, July 2017, <https://www.nationalfamilyplanning.org/document.doc?id=3147&erid=1697547>.

⁴³ “Social Security Changes.”

qualifying functional disability), or (b) are over the age of 65. The stringency with which a functional disability is defined means that more than six out of ten people who self-report such a disability do not qualify.⁴⁴ The maximum benefit is 74% of the Federal Poverty Line, or \$943/month as of 2024 for an individual and \$1,415/month for a married couple who both qualify.⁴⁵ There is no previous work requirement for SSI, but payments are lowered if a person is working while receiving it.⁴⁶ The amount that one qualifies for is also reduced based on any “income” one receives, including “in kind” support such as food and shelter.⁴⁷ Some people who qualify for SSDI in an amount that is less than the maximum for SSI get SSI as well.⁴⁸ A person also cannot have more than \$2,000 in assets (\$3,000 for married couples), although the values of one’s home and automobile are not factored into that calculation.⁴⁹

A PLAHIV who relies on Social Security benefits potentially makes decisions driven by the requirements of these programs instead of what they wish to do or what is best for their health. It has been shown that PLHIV who are employed have better physical and mental health outcomes.⁵⁰ However, many program recipients may refrain from returning to work as doing so could cause them to lose their immediate access to benefits.⁵¹ “This is especially true for those that may be virally suppressed, but have multimorbidities that exacerbate difficulties with activities of daily living.”⁵² On the other hand,

because Social Security retirement payments are typically higher than SSDI, a person’s financial or family situation may force them to remain in the workforce longer than they might otherwise be based on either their health or the desire to maximize their benefits.⁵³ And once a PLAHIV does retire, if they had an inconsistent work history because of living with HIV, their Social Security payments will be reduced, affecting their ability to support themselves and maintain their autonomy.⁵⁴

A person living and aging with HIV who relies on Social Security benefits potentially makes decisions driven by the requirements of these programs instead of what they wish to do or what is best for their health.

Furthermore, the so-called marriage penalty may influence the kinds of relationships and commitments that a PLAHIV can engage in so as not to lose benefits. A married couple who both qualify for SSI does not receive the equivalent of two times the benefits for a single person but 1.5 times, thus reducing the benefit by being married.⁵⁵ Similarly, if a PLAHIV needs to continue to receive SSI, marriage could force their partner to “spend down” their assets so that

⁴⁴ MaryBeth Musumeci and Kendal Orgera, “Supplemental Security Income for People with Disabilities: Implications for Medicaid,” KFF, June 23, 2021, <https://www.kff.org/medicaid/issue-brief/supplemental-security-income-for-people-with-disabilities-implications-for-medicaid/>

⁴⁵ “SSI Federal Payment Amounts for 2024,” Social Security Administration, <https://www.ssa.gov/oact/cola/SSI.html>.

⁴⁶ Musumeci, “Supplemental Security Income.”

⁴⁷ Musumeci, “Supplemental Security Income.”

⁴⁸ Musumeci, “Supplemental Security Income.”

⁴⁹ Musumeci, “Supplemental Security Income.”

⁵⁰ Sean E. Bland and Jeffrey S. Crowley, *HIV Policy in the United States: Meeting the Needs of People Aging with HIV on the Path to Ending the HIV Epidemic*, May 2021, 14, <https://oneill.law.georgetown.edu/wp-content/uploads/2021/05/Meeting-the-Needs-of-People-Aging-with-HIV.pdf>.

⁵¹ The Social Security Administration has created programs to incentivize people returning to work, such as the Ticket to Work Program. However, the different benefit programs have different income limits that impact the amount of benefits, if any, one continues to receive if they begin to work. Working that impacts one’s ability to remain in a benefits program will also potentially impact one’s ability to qualify for Medicare or Medicaid, though cancellation should not be either automatic or immediate. *Working While Disabled: How We Can Help*, Social Security Administration, 2024, <https://www.ssa.gov/pubs/EN-05-10095.pdf>.

⁵² HealthHIV, Third Annual Survey, 22.

⁵³ Blanton, “Your Social Security.”

⁵⁴ Sarah Elizabeth Adler, “Older Adults with HIV Reflect on the ‘Aging of an Epidemic,’” AARP, August 2, 2022, <https://www.aarp.org/health/conditions-treatments/info-2021/older-adults-living-with-HIV.html>.

⁵⁵ Musumeci, “Supplemental Security Income.”

the PLAHIV does not lose the benefit. This can mean that to protect their finances some couples who may wish to marry are unable to do so.⁵⁶

The asset limit required for SSI can also be detrimental to the ability of a single PLAHIV to make unhindered choices about their future. Because they are required to keep their assets low, below \$2,000, they cannot create any kind of safety net in case an emergency arises, which runs counter to the advice that people generally are given regarding savings.⁵⁷ In addition, it reduces their ability to save even for a nonemergency, such as for a deposit on an apartment (a home that one owns is not considered an asset for SSI purposes). To qualify for the monthly income that they need to survive, PLAHIV are forced to balance on a knife's edge, hoping that nothing goes wrong instead of being able to prepare in case something does.

The restrictions on options and choice experienced by PLAHIV is even clearer once Medicaid and Medicare are factored in, for which many PLHIV qualify through SSI or SSDI. Medicaid is free or low-cost health insurance for low-income people that is administered by the states; it has no work history requirement. Some states, however, have rejected the Medicaid expansion portion of the American Affordable Care Act, or have adopted only certain provisions of the expansion.⁵⁸ But in states that have signed onto the expansion, people who qualify for SSI also qualify for Medicaid with

no waiting period. As of 2022, even in all the Medicaid expansion states (except California and Arizona), participants, on reaching age 65 or qualifying for Medicare, must spend down their assets, typically to \$2,000 for an individual or \$3,000 for a couple, or lose their Medicaid if they have it.⁵⁹

People who have received SSDI for 24 months qualify for Medicare. Medicare is a federally operated health insurance plan. It covers people who are over the age of 65 and/or have a qualifying disability as long as they have the appropriate work history.⁶⁰ As of 2020, more than 25% of PLHIV are covered by Medicare.⁶¹ This number is likely to dramatically increase as more PLAHIV become eligible as they reach age 65.⁶² Many PLAHIV qualify for both federal health insurance programs, using Medicaid to pay for things that Medicare does not cover, such as long-term care.⁶³ So PLAHIV's necessary access to medical care may be tied to whether they follow the rules to receive SSI or SSDI. Access to SSI and SSDI, and through them to Medicaid and Medicare, is just one example of the many ways that having a low income affects PLAHIV's ability to have full and unfettered control over their choices. One should not need to choose between getting married and obtaining healthcare, especially when the formalization of that relationship may further impact who the government favors for making medical decisions if the person is incapacitated.

⁵⁶ In discussing her participation in a staged "commitment ceremony" protesting the marriage penalty, one disabled woman stated, "I'm going to wear an ivory dress. There's this idea that at a wedding, you wear a white dress to symbolize purity. I'm wearing ivory to symbolize that for disabled people, we don't have the purity of the fundamental right to get married without risking our lives." Sara Luterman, "Marriage Could Mean Losing Life-saving Benefits for People with Disabilities. So They're Protesting," *The 19th*, September 13, 2023, <https://19thnews.org/2023/09/disability-advocates-marriage-equality-commitment-ceremony/>.

⁵⁷ A quick google search reveals that most financial planners recommend having a safety net of 6 times one's monthly expenses saved always in case of emergencies. For one, of many examples: "Take Time to Create a Financial Emergency Plan," State Farm, last accessed May 23, 2024, <https://www.statefarm.com/simple-insights/financial/create-a-financial-emergency-plan>.

⁵⁸ "Medicaid - Glossary," HealthCare.gov, accessed May 23, 2024, <https://www.healthcare.gov/glossary/medicaid/>; Musumeci, "Supplemental Security Income."

⁵⁹ Amber Christ et al., *Expanding Health Care Affordability for Older Adults and People with Disabilities: A Guide for State Medicaid Advocates*, "Justice in Aging," March 2022, <https://justiceinaging.org/wp-content/uploads/2022/03/Expanding-Health-Care-Affordability.pdf>.

⁶⁰ "Public Benefits and HIV in the US," The Well Project, November 3, 2023, <https://www.thewellproject.org/hiv-information/public-benefits-and-hiv-us>.

⁶¹ Miles Meline, "People with HIV on Medicare Have Large Gaps in Treatment," Penn LDI, February 26, 2024, <https://ldi.upenn.edu/our-work/research-updates/people-with-hiv-on-medicare-have-surprisingly-large-gaps-in-treatment/>.

⁶² Meline, "Large Gaps in Treatment"; Lindsey Dawson et al., "Medicare and People With HIV," KFF, March 27, 2023, <https://www.kff.org/hiv/aids/issue-brief/medicare-and-people-with-hiv/>.

⁶³ Cahill, "Growing Older," 11.

GUARDIANSHIP: THE ULTIMATE LOSS OF CONTROL

The case of the pop star Britney Spears dragged the issue of guardianships and conservatorships into the limelight, with Spears’s fight to dissolve her guardianship in national news. Some of the public got to see for the first time what a blunt tool guardianship is. But for many others, the pitfalls of guardianships were already well known. It is estimated that there are 1.3 million adult guardianships (as of 2018), and through them, the court and appointed guardians control more than \$50 billion in assets.⁶⁴ The Center for Elders and the Court defines guardianship as “a relationship created by state law in which a court gives one person or entity (the guardian) the duty and power to make personal and/or property decisions for another (the ward).”⁶⁵ Guardianship is governed by state law, and different states may use different terms, but the generally agreed-on categories are:

Guardian: An individual or an organization named by the court order to exercise some or all powers over the person and/or the estate of an individual.

Guardian of the Person: A guardian who possesses some or all power with regard to the personal affairs of the individual.

Guardian of the Estate: A guardian who possesses some or all powers with regard to the real and personal property of the individual (often referred to as conservators or fiduciaries).⁶⁶

Guardians who have complete control are known as plenary guardians. Guardians who have partial control, which is technically “preferred,” are known as limited guardians.⁶⁷ However, it is more common that a plenary guardianship will be instituted instead of a limited one and that it will remain in place until it is affirmatively terminated by the court (there is no automatic lapse date) or until the person subject to the guardianship dies.⁶⁸ Guardianship proceedings can be initiated by any interested person or entity — such as a family member, hospital, nursing home, adult protective services, etc. — who decides to file a petition stating that a person has impaired decision-making abilities. But if a guardianship is put into place, that filer does not necessarily become the guardian.⁶⁹ The court determines who it thinks would be the best guardian, with a preference for family, though there has been an expansion of the network of “professional guardians,” that is, people who serve as guardians for a fee, or a Public Guardian.⁷⁰

In deciding whether to appoint a guardian, the court evaluates whether the person against whom the guardianship is sought is incapacitated. That means that the court decides if the person is an “individual who lacks the ability to ‘receive and evaluate information or to make or communicate decisions to the point that the person’s ability to care for his or her health, safety or self is compromised.’”⁷¹ Guardians may be appointed to help protect people when the court determines that they are susceptible to fraud or undue influence.⁷² In many states, the

⁶⁴ National Council on Disability, *Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination*, February 22, 2018, 65, <https://www.ncd.gov/assets/uploads/docs/ncd-guardianship-report-accessible.pdf>.

⁶⁵ “Guardianship Basics,” Center for Elders and the Courts, March 28, 2022, <https://www.eldersandcourts.org/guardianship-old/guardianship-basics-old/>.

⁶⁶ “Guardianship Basics.”

⁶⁷ Pennsylvania is one state where the law affirmatively states that limited guardianships are preferred. The Advisory Council on Elder Justice in the Courts, *First Edition of the Judicial Bench Book on Guardianships*, 2020, <https://www.pacourts.us/Storage/media/pdfs/20210526/235039-file-10135.pdf>; “Guardianship Basics.”

⁶⁸ Jim Berchtold, *Addressing Bias in the Guardianship Process*, “Justice in Aging,” February 2024, <https://justiceinaging.org/wp-content/uploads/2024/02/Addressing-Bias-in-the-Guardianship-Process-Issue-Brief.pdf>.

⁶⁹ “Establishment of Guardianships,” Center for Elders and the Courts, March 28, 2022, <https://www.eldersandcourts.org/guardianship-old/establishment-of-guardianships-old/>.

⁷⁰ “Establishment of Guardianships.”

⁷¹ “Establishment of Guardianships.”; Unif. Guardianship & Protective Procs. Act §102(5)(1997).

⁷² Valerie Bradley et al., *National Core Indicators Data Brief: What Do NCI Data Reveal About the Guardianship Status of People with IDD?*, April 2019, https://legacy.nationalcoreindicators.org/upload/core-indicators/NCI_GuardianshipBrief_April2019_Final.pdf.

In Texas, Providing Alternatives to Restrictive Guardianships

Nationally, the number of people under guardianship is skyrocketing. In Texas in 2013, the state had over 46,000 active guardianships, and in 2019, there were 51,250 that controlled \$4.9 billion in assets.¹ Concurrent with this increase in the number of guardianships is the increasing recognition that guardianships strip people of their rights, often with limited due process, causing a condition known as “civil death.”²

In 2015, Texas became the first state to legally recognize the validity of “supported decision-making” agreements as alternatives to guardianship. This is based on the idea that guardianship should use the least restrictive means necessary to promote and protect a person’s well-being and that if guardianship can be avoided the court must do so.³

“Broadly speaking, ‘supported decision-making’ refers to an arrangement where an individual with a disability works with one or more trusted supporters who help them make important decisions.”⁴ Before being able to impose a guardianship generally, the court must first find that less restrictive means have been considered.⁵ These supportive

decision-making agreements are key to preventing guardianships.⁶

Texas created a supported decision-making form that can be used by a potential “ward” to help a person identify what support they actually need and/or want. Both the potential “ward” and those supporting them agree to abide by the terms of the agreement.

In 2015, Texas became the first state to legally recognize the validity of “supported decision-making” agreements as alternatives to guardianship.

In Texas, the person for whom a guardianship is sought has a right to counsel in the proceedings.⁷ This is consistent with other areas of law where there has been found to be a right to counsel, such as in dependency proceedings, based on the potential level of restriction a guardianship can place on someone. Not only do they have the right

¹ Megan Morgan, “Alternatives to Guardianship for Adult Texans with Intellectual and Developmental Disabilities,” The ATC, August 2015, https://www.hearcoftexas.org/wp-content/uploads/Guardianship_White_Paper-1.pdf; Texas Guardianship Reform: Protecting the Elderly and Incapacitated, The State of Texas Office of Court Administration, 2019, https://www.txcourts.gov/media/1443314/texas-guardianship-reform_jan-2019.pdf.

² Due process is a form of procedural protection constitutionally afforded to important rights.

³ “Using Supports and Services as an Alternative to Guardianship,” Disability Rights Texas, November 17, 2018, <https://disabilityrightstx.org/en/handout/alternatives-to-guardianship-supports-services/>.

⁴ Eliana J. Theodorou, “Supported Decision-Making In the Lone Star State,” *New York University Law Review* 93 (2018): 975.

⁵ Theodorou, “Supported Decision-Making,” 997; Texas Estates Code 3§ 1054.151 (2023).

⁶ Disability Rights Texas, “Overcoming Civil Death: A Report on Needed Legal Reforms for People Seeking Restoration of Rights,” accessed July 3, 2024, <https://disabilityrightstx.org/wp-content/uploads/2022/09/Overcoming-Civil-Death-Needed-Legal-Reforms-for-Rights-Restoration.pdf>.

⁷ §1054.001.

to hire an attorney if they so desire and financially can, but the court will appoint them an attorney *ad litem* if they cannot or do not wish to hire. Texas law makes explicit what the duties of these appointed attorneys are, including such details as their responsibility to interview their client and to review accessible documents and information to prevent less-than-zealous representation by appointed counsel.

In 2023, Texas made major updates to its guardianship laws; SB1624 expanded the right to counsel for guardianship hearings to include hearings where a “ward” has petitioned to have their rights reinstated. This expansion will hopefully counteract the relative permanence of guardianship decisions. Counsel for the “ward,” regardless of whether hired privately or appointed, is now mandated to be given access to all records related to the guardianship case, including medical records and psychological assessments. Previously, some public interest attorneys who tried to represent “wards” in reinstatement or modification hearings had found their requests for such records opposed by guardians who did not wish for the guardianship to be dissolved.⁸

One particularly important change was the addition of language stating that attorneys had to “represent the proposed ward’s interests, including their expressed wishes.” Attorneys in a variety of cases where the client is alleged to be incompetent (unable to assist in their case) are typically mandated to use one of two types of “interests” to guide their representation.

Expressed interest is where an attorney is bound to fight for their client’s goals, regardless of whether or not they personally believe that the client’s goals are feasible or “right.” Although attorneys typically have a lot of leeway as to the strategy they employ to meet those goals, what they ultimately ask for in court must be what their client wants. They are not permitted to substitute their own judgment as to what is in their client’s best interests.

Best interest is a standard by which, after investigation, an attorney is mandated to put forward what they believe to be the best choice for their client, even if it is contrary to their client’s wishes. For example, an attorney who believes their client needs a guardian, under the best interest standard, would argue for a guardianship to be created, even if that client adamantly opposed it.

The changes to the Texas law shifted the mandate for guardianship attorneys from representing their clients’ “best interests” to representing their “expressed interests.”⁹

Expanding the ways that potential “wards,” including aging people, have to combat guardianship and “civil death” is a way of providing for them to retain the “dignity of risk.” “People with disabilities, like their non-disabled peers, want to be able to make their own choices, even if these involve risk.”¹⁰

⁸ Disability Rights Texas, “Overcoming Civil Death.”

⁹ “Your Right to Choose a Lawyer for Your Guardianship Hearing,” Disability Rights Texas, December 14, 2023, <https://disabilityrightstx.org/en/handout/right-choose-lawyer-guardianship-hearing/#:~:text=in%20a%20guardianship-,You%20can%20hire%20a%20lawyer%20to%20represent%20you%20in%20a,capacity%20to%20hire%20a%20lawyer>.

¹⁰ Morgan, “Alternatives.”

court must appoint an attorney to represent the person against whom the guardianship is sought if the person cannot hire their own attorney.⁷³

A guardianship, especially a full guardianship, is a powerful and blunt use of the government's power. The Pennsylvania Guardianship Bench Book cautions:

The determination that a person is incapacitated and the appointment of a guardian are among the most significant deprivations of personal liberty and autonomy that a court can impose. Such a deprivation requires that the due process rights of the alleged incapacitated person (AIP) be given the highest level of protection, as required by the United States Constitution for any deprivation of liberty. A person for whom a guardian is appointed faces losing the basic right to make their own decisions, enjoyed by all adults, and will no longer have control of their life, liberty, or property.⁷⁴

People living and aging with HIV who have other marginalized identities, especially older Black and brown adults, are at a higher risk of being found incapacitated, not because of an inability to make personal choices but because the court does not agree with the choices they make.

Unlike in criminal cases, in guardianship proceedings, there is no constitutional right to counsel (meaning that an attorney is required to be appointed if a person cannot afford one). However, because of the gravity of the decision, many jurisdictions have created a right to counsel for guardianship proceedings. As in

other instances where PLAHIV are entangled in the legal system, they face unique challenges when they are in guardianship proceedings that would be better addressed if they had access to counsel.

In a guardianship proceeding, the court examines all aspects of a person's life and weighs judgment on whether the person is making good decisions. However, in order to "judge" another person's decisions, one needs to have a high level of cultural competence, to understand the reasons why a person may make or prioritize certain choices over others, and to be able to recognize and address their own implicit biases that come into play when making such a subjective determination. "Every person operating within the larger guardianship system possesses some level of implicit bias, including judges, attorneys, court staff, medical doctors, psychiatrists, and public, private, and family guardians."⁷⁵ Implicit bias is "the human tendency to subconsciously associate certain stereotypes with particular categories of people."⁷⁶

Judgments that a PLAHIV may make for their safety, or out of necessity, because of the stigma and bias that they face, may appear irrational to someone who is viewing the decisions without acknowledging that context. For example, imagine an aging trans woman living with HIV who has ended up in guardianship proceedings after being hospitalized from a fall. At the hospital, her viral count was high because she had been unable to afford both her HIV medications and her hormones. Imagine also that she had fired her previous home health aide for not respecting her gender identity and thereafter struggled to care for her everyday needs unassisted, and the effect that this would have on the photos of the condition of her home that would be shown to the judge. A judge determining whether the woman has the capacity to care for herself could find that the choices she had made to prioritize her gender identity over her HIV care and living conditions

⁷³ "Guardianship: Key Concepts and Resources," U.S. DOJ: Elder Justice Initiative, October 31, 2023, <https://www.justice.gov/elderjustice/guardianship-key-concepts-and-resources#protections>.

⁷⁴ Advisory Council, Judicial Bench Book.

⁷⁵ Berchtold, Addressing Bias.

⁷⁶ Berchtold, Addressing Bias.

mean that she does not have the capacity to make her own decisions, in part because the judge would have chosen differently in the same situation.⁷⁷ So PLAHIV who have other marginalized identities, especially older Black and brown adults, are at a higher risk of being found incapacitated, not because of an inability to make personal choices but because the court does not agree with the choices they make.⁷⁸

Alternatives to Guardianship

Currently, in many states, the court in a guardianship proceeding is directed to investigate the least restrictive alternatives to guardianship.⁷⁹ It is important that aging people be aware of these alternatives so that they can potentially advocate for them during a guardianship hearing if the court does not explore them *sua sponte*, or by itself, with no party asking. These alternatives can be used singly or together to assist in the area(s) where a person may be struggling, without stripping the individual of more decision-making power than necessary. Some examples are:

Programs and Services: Has a person ended up in guardianship court because they have been missing doctors' appointments? Maybe all they need is access to transportation. Are they not eating, or have they no way to get food? Maybe they need to be connected to a meal program such as Meals on Wheels. There are many situations that can be mistaken for poor decision making that are instead due to a lack of access to resources. Getting a person enrolled in a day program or an in-home service program

Currently, in many states, the court in a guardianship proceeding is directed to investigate the least restrictive alternatives to guardianship.

may be all that the person needs in lieu of a guardianship. Or the court can provide access to a case manager who can assist the person with tasks instead of removing the person's decision-making power.⁸⁰

Representative Payee (rep payee): A rep payee can be appointed by the court and can be a friend, a family member, or even a professional rep payee. A rep payee is responsible for managing a person's Social Security benefits, assuring that bills are paid on time, and that a person vulnerable to fraud has a layer of protection.⁸¹ A recent change is that you can now designate someone to serve as your rep payee in advance.⁸²

Online Banking: For people who do not receive SSI or Veterans benefits, assistance with money management can be as simple as setting up a combination of direct deposit and automatic bill pay.⁸³

Trusts: "Finances can also be managed through the creation of a trust, a legal entity able to hold property and assets that are managed by a fiduciary (the trustee) for the benefit of the beneficiary pursuant to the instructions in the trust documents."⁸⁴

⁷⁷ "Capacity doctrine should also take steps to insure that the determination of capacity is done in a culturally sensitive way that takes into account the unique socio-legal status of LGBT individuals. For example, the fear of encountering anti-LGBT bias may cause older LGBT individuals to make choices that could appear irrational if they are viewed out of context." Knauer, "LGBT Issues and Adult Guardianship."

⁷⁸ ["T]he likelihood that an older adult of color will come into contact with anyone during the guardianship process who looks like them, hails from their same community, shares their same history, or holds their same cultural values is slim, while the likelihood remains high that they may be negatively impacted during that process by bias because of their race, ethnicity, cultural identity, socioeconomic level, sexual orientation, etc." Berchtold, Addressing Bias.

⁷⁹ Jim Berchtold, Least Restrictive Alternatives to Guardianship, April 2024, <https://justiceinaging.org/wp-content/uploads/2024/04/Less-Restrictive-Alternatives-to-Guardianship.pdf>.

⁸⁰ Berchtold, Least Restrictive.

⁸¹ Disability Rights Pennsylvania, Chapter 10: Guardianship in Pennsylvania, February 2018, 3, <https://www.disabilityrightspa.org/wp-content/uploads/2018/04/CCSDM-11E.pdf>.

⁸² Advance designation of Representative Payee," Social Security , accessed July 30, 2024, <https://www.ssa.gov/payee/>.

⁸³ Berchtold, Least Restrictive.

⁸⁴ Berchtold, Least Restrictive.

Not all of these options are equally accessible alternatives to guardianship for everyone. This is because those who have been historically disenfranchised from systems that assist in the accumulation of generational wealth or from the estate planning that is necessary to pass on such wealth, like Black and Latine people, may not even be aware of what options exist or may not have access to programs tailored to their needs.⁸⁵ However, utilizing these options can be a tool for PLAHIV to either avoid guardianship proceedings altogether or avoid having a guardianship imposed on them.

There has also been a concerted move toward supportive decision-making agreements, both formal and informal.⁸⁶ Supportive decision-making agreements involve the aging person's identification of people in their life they will turn to for help in understanding the issues involved in a decision and for advice as to the best

Aging people should not have to make themselves unable to weather a financial emergency because of having to spend down their assets to keep Medicaid.

course of action.⁸⁷ The group can include family, friends, and professionals such as social workers. Without the execution of other advanced planning documents, the members of one's decision support team do not have the legal authority to substitute their decision for that of the aging person.⁸⁸ In some ways, this option can function as the formalization of the family and chosen family networks that a PLAHIV has and that can be identified and structured before any anticipated loss in the person's ability to make decisions without support.

How Can People Living and Aging with HIV Retain Decision-Making Rights?

An important way that PLAHIV can preserve their decision-making rights is by preemptively executing any or all of a list of legal documents, commonly known as “advanced planning documents,” that either explicitly state their desires or affirmatively establish who they want to make decisions for them if they become incapacitated. Though these documents are often included in lists of alternatives to guardianship, they have been separated here for two reasons: (1) because, unlike the other alternatives to guardianships listed earlier, which can be used in guardianship proceedings even if a finding of incapacity has been made, these

documents must be executed when the person has the capacity to do so; and (2) because they represent a form of self-advocacy or steps that PLAHIV can take to protect themselves if they have concerns about the future.

These documents are governed by state law, and every state may not offer all of them, call them the same thing, or have the same requirements to validate them. PLAHIV should consult with an attorney, if possible, to make sure that the documents are legally binding and can be used to enforce their decisions if they are unable to express them. Many PLAHIV, however, have cited their lack of documents as

⁸⁵ Berchtold, Least Restrictive.

⁸⁶ For a chart listing what state laws, if any, govern supported decision making, see Abigail Hartnett, Supported Decision Making: A Statutory Chart, June 2023, https://www.americanbar.org/content/dam/aba/administrative/law_aging/2022-sdm-1st-rstctd-altntvs.pdf.

⁸⁷ David Godfrey, Advance Planning: An Overview for Advocates, February 2023, https://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/supported-decision-making/.

⁸⁸ Godfrey, Advance Planning.

Restorative Justice: A Remedy for Elder Abuse in California

Elder abuse is “a single, or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person.”¹ It can take the form of neglect, financial exploitation, or emotional, psychological, physical, or sexual abuse.²

In 2023, California passed a law establishing the right for all victims of a crime to be informed of the availability and benefit of restorative justice programs

Approximately 10% of older adults in the United States experience some form of elder abuse each year.³ However, many people harmed by elder abuse may not wish to address the abuse through the criminal legal system. This is oftentimes because the perpetrator of the abuse is a family member, who they do not want to expose to the penalties or abusive treatment of that system.⁴ They may be afraid that if they admit to the abuse

they will be judged incompetent (i.e., unable to take care of themselves) and lose their autonomy.⁵ In addition, many marginalized folks may not trust the system due to historical (and present) systemic racism and oppression. Or, as is the case for many Black elders, they may simply be unable to access the system due to the way the system casts them as unworthy victims, essentially causing them to be revictimized.⁶

“Restorative justice principles focus on repairing and making amends for harm caused in a way that is meaningful to and agreed upon by the victim, and that focuses on transformation, healing, and reintegration of the parties into their community.”⁷

In 2023, California passed a law establishing the right for all victims of a crime to be informed of the availability and benefit of restorative justice programs.⁸ It reads in relevant part:

(15) For the victim, to be notified of the availability of community-based restorative justice programs and processes available to them, including, but not limited to, programs

¹ Mary Helen McNeal et al., “Elder Restorative Justice,” *Cardozo Journal of Conflict Resolution* 21 (2019): 93-94.

² David Burnes et al., “Rise: A Conceptual Model of Intergrated and Restorative Elder Abuse Intervention,” *The Gerontologist* 63, no. 6 (June 15, 2022), <https://doi.org/10.1093/geront/qnac083>.

³ Burnes et al., “Rise.”

⁴ Burnes et al., “Rise.”

⁵ Burnes et al., “Rise.”

⁶ Juanita Davis, “Increasing Access to Healing Services and Just Outcomes for Older African American Crime Survivors: A Toolkit for Enhancing Critical Knowledge and Informing Action within the Crime Victim Assistance Field Guide,” Vera Institute of Justice, 2020, 28, <https://reachingvictims.org/wp-content/uploads/2020/07/Increasing-Access-Guide-1.pdf>.

⁷ Burnes et al., “Rise.” Restorative justice is sometimes negatively viewed as a system of addressing crimes without consequences to the harmer. It is instead a system that centers the needs of the harmed, and makes sure that any consequences for the harmer are beneficial to the harmed person’s healing process, which allows for a much broader definition of “consequences” than incarceration.

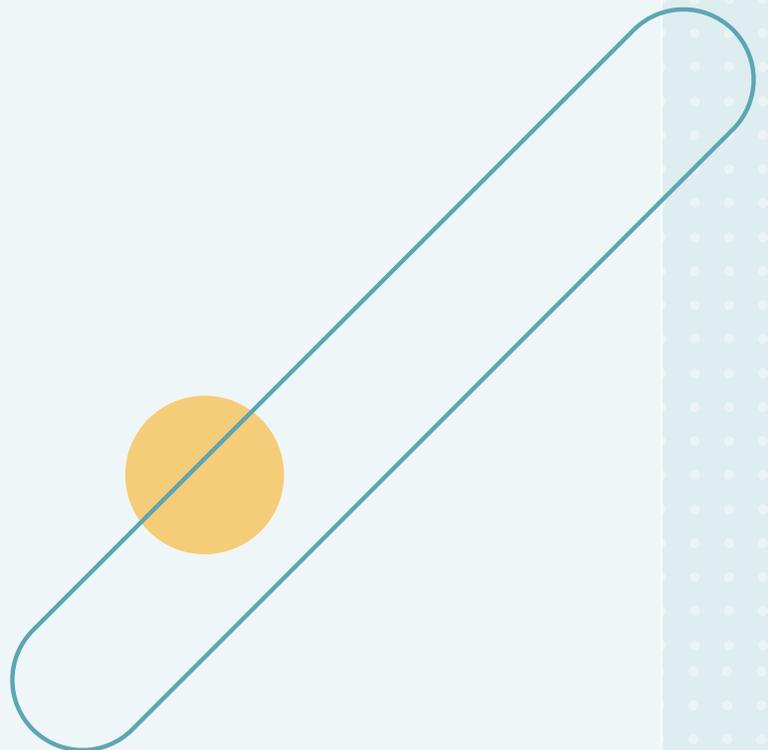
⁸ Restorative Justice Program, A.B. 60, California (2023).

serving their community, county, county jails, juvenile detention facilities, and the Department of Corrections and Rehabilitation. The victim has a right to be notified as early and often as possible, including during the initial contact, during follow-up investigation at the point of diversion, throughout the process of the case, and in post conviction proceedings.⁹

This requirement opens a door for the increased utilization of restorative justice programs for older people that California agencies, led by the California Elder Justice Coalition, have been advocating for.¹⁰ Restorative justice programs have been growing in popularity nationwide, but once the criminal legal system is involved they are typically offered only at the post-conviction phase. This law is different in that actors in the system are required to make the option be known at multiple points during the criminal legal process (though they are not obligated to provide it themselves).

Accessibility to restorative justice would allow those harmed by elder abuse to have a way to address the harms and avoid the pitfalls of involvement in the criminal legal system. Since it not only focuses on the harmed but also offers opportunities for healing for the harmer and the community, restorative justice is a framework well designed to address many issues of elder abuse.

Accessibility to restorative justice would allow those harmed by elder abuse to have a way to address the harms and avoid the pitfalls of involvement in the criminal legal system.



⁹ California Penal Code §679.02 (2023).

¹⁰ Lisa Nerenberg, "Restorative Justice: Can It Heal the Harm of Elder Financial Abuse," *Next Avenue* August 9, 2021, <https://www.nextavenue.org/elder-financial-abuse/>.

a major concern as they age.⁸⁹ The Research on Older Adults with HIV Study 2 has shown that while white people older than 50 are statistically likely to have at least one directive set up, Black people over 50 are less likely to have done any advanced care planning.⁹⁰ Some states, state bar associations, and nonprofits have online samples of valid documents for their states in an effort to make these planning documents more accessible. Examples of the kinds of advanced planning documents that may be available in a state are as follows:

LIVING WILL

Although frequently conflated with a “do not resuscitate (DNR)” order, a living will specifies what desired treatment, if any, a person wants if they do not have the capacity to make a decision (e.g., are unconscious) at the time of treatment.⁹¹

HEALTHCARE PROXY (MEDICAL POWER OF ATTORNEY)

A healthcare proxy can specify wishes about healthcare, but it is primarily important because it gives another person the legal ability to make one’s healthcare decisions.⁹² The proxy can be used to make sure that whoever is making one’s healthcare decisions is the person that one wants to have that power.⁹³

PHYSICIAN ORDERS FOR LIFE- SUSTAINING TREATMENT (POLST)

POLST are medical care orders that are created in consultation with one’s healthcare providers that establish the kind of care that the person wants when seriously or terminally ill. They are different from a living will in that they are treatment-specific; that is, they are written based on what is happening at the time they are drafted in response to a specific medical

condition. They can address a wide range of topics, such as pain management and specific treatment options.⁹⁴

POWER OF ATTORNEY

A power of attorney is a document that authorizes a person to transact business on behalf of another individual and makes their actions legally binding on the individual.⁹⁵

Having these documents in place means that someone else’s decision making can only be substituted for one’s own in the ways specified. Although the variety is not available in all states, some of the documents are specifically “springing” documents, meaning that they do not take effect unless certain conditions are met.⁹⁶ Once they are made available to the court, these documents should cause a guardianship proceeding to be halted, as they indicate the existence of substitute decision makers chosen when capacity was not at issue.

⁸⁹ Community Solutions, *What Matters to YOU? Needs Assessment for People Living with HIV*, December 2019, 40, Table 27, <https://www.in.gov/health/hiv-std-viral-hepatitis/files/2019-Needs-Assessment-for-People-Living-with-HIV-Final-Report.pdf>.

⁹⁰ Paul Nash et al., “Failing to Plan Is Planning to Fail: Utilization of Advanced Care Directives in Adults Living With HIV,” *Innovation in Aging* 5, no. S1 (2021): 219, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8682212/pdf/igab046.845.pdf>.

⁹¹ Annie L. Nguyen et al., “Perceptions of the Importance of Advance Care Planning during the COVID-19 Pandemic among Older Adults Living with HIV,” *Frontiers in Public Health* 9 (February 5, 2021): 2, <https://doi.org/10.3389/fpubh.2021.636786>.

⁹² Nguyen, “Perceptions of Importance,” 2.

⁹³ Justice in Aging, *Stories from the Field*, 12.

⁹⁴ Godfrey, *Advance Planning*.

⁹⁵ Berchtold, *Least Restrictive*; Godfrey, *Advance Planning*.

⁹⁶ National Council, *Beyond Guardianship*, 124.

How Can Advocates Promote the Retention of Decision-Making Power?

There is a complex network of state and federal policies that have an impact on the ability of PLAHIV to be truly free to make the choices they desire. Some government policies restrict choice through eligibility requirements, such as SSI, and some government programs, like guardianship, threaten to strip one's decision-making power away entirely. Overall, government benefit programs should be geared to broaden and expand their lists instead of cutting people off. Purging the lists of people who "do not deserve" benefits and cutting administrative costs should not affect people's eligibility for the vital, if inadequate, safety net that these programs represent. It is shameful how many people are rejected by SSDI when they first apply, only to get approved after an appeals process that can take years. Aging people should not have to make themselves unable to weather a financial emergency because of having to spend down their assets to keep Medicaid. Programs need to be flexible and not punitive, allowing people to use funds from the programs in ways that provide for their actual needs.

There are other policies that advocates can advance to improve services and make them more accessible to PLAHIV. There is an appreciable movement in the United States, spurred by the recent rules update for the Older Americans Act, to a right to counsel in guardianship proceedings, although it is not yet a requirement. In the rules for the Act, the Administration for Community Living made clear that all funds from the federal government earmarked for guardianship proceedings are supposed to be used only for defense, not for initiating proceedings.⁹⁷ Even if there is no national requirement for a right to counsel, the states, and sometimes municipalities, can institute them — similar to how both New York City and Philadelphia have a right to counsel for tenants in eviction proceedings. Likewise,

people can advocate for programs to provide legal counsel to aging people so that they can get their advanced planning documents set up.

The policies that intersect to constrict and control decision making must be overhauled to respect the decision-making authority of people living and aging with HIV.

Simultaneous with the expansion of access to counsel, educational campaigns should inform people of alternatives and provide as many self-help options as possible so that aging people can address these concerns themselves. PLAHIV should be empowered to navigate these systems without needing an attorney. Overall, the policies that intersect to constrict and control decision making must be overhauled to respect the decision-making authority of people living and aging with HIV.

⁹⁷ Administration for Community Living, "Older Americans Act."



“I wanted to thank you.
If it wasn't for you, I'd never have known
I had a right to be me.”

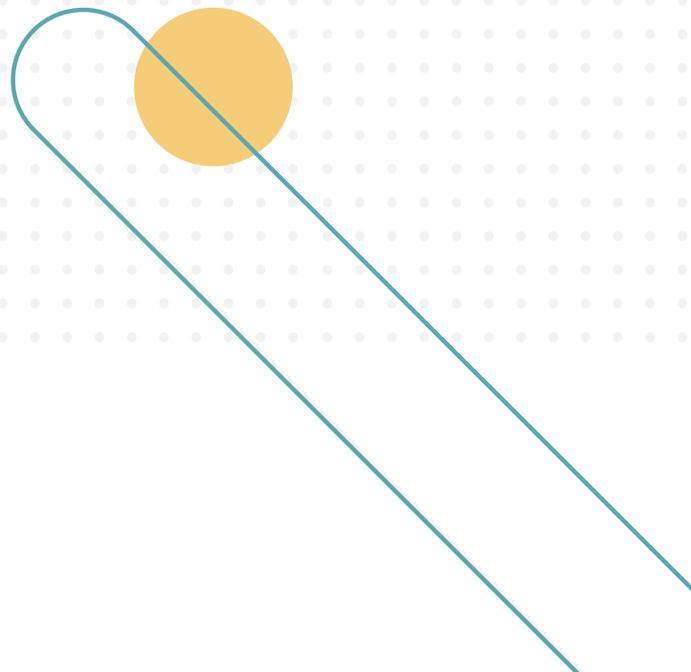
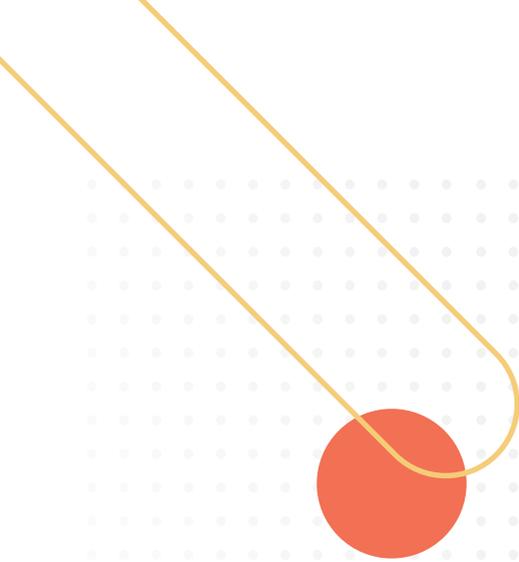
– LESLIE FEINBERG,
*STONE BUTCH BLUES*¹

Conclusion

It was important that each section of this primer not only include a description of the challenges faced by People Living and Aging with HIV (PLAHIV) but also areas of self advocacy, advocacy that their supporters can engage in, and even examples of some places that are “doing it right” (such as New York’s Elder Care Bill of Rights). Just as there are myriad forms of discrimination and administrative roadblocks faced by people living with HIV to aging with dignity with unhampered decision-making capacity, there are accessible options to best prepare for the future.

PLAHIV have a long history of advocacy in many areas, including calling for the Meaningful Involvement of People with HIV/AIDS (MIPA) in the Denver Principles, confronting several government agencies over access to life-saving medications, and fighting at every turn for the right to survive and live as their authentic selves. This primer builds upon that work with the ultimate goal of helping PLAHIV identify the laws and rules that impact their lives and highlight strategies to improve them. And it will be this history that will be of utmost importance when advocating for many of the changes identified in this work.

¹ Leslie Feinberg, *Stone Butch Blues* (Ithaca, NY: Firebrand Books, 1993), 530.



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