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Advocating for Women Living With HIV in Prisons or Jails in the US

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Image



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Note: This fact sheet is focused on prisons and jails in the United States. Some issues, such as interruption of HIV treatment, are likely similar across the world. However, legal systems, correctional institutions, and avenues for addressing problems are very different from one country to another. The information below may therefore not apply outside the US.

Coronavirus note: Early in the COVID-19 pandemic, many prisons and jails had been on lockdown (no visitors, limited or no access to telephones, confinement to cell or bed, etc.) to prevent the spread of the virus. Advocacy – including by formerly incarcerated people and those with loved ones in prison – resulted in some jails and prisons releasing people early to relieve overcrowding and the terrible effects of [COVID-19](#) in US prisons. Their work resulted in a 14% drop in the incarcerated population in the US. However, that progress had begun to stall within a year of the start of the pandemic and the number of people in prison is rising again. These and other conditions may affect your advocacy work.

Introduction

Advocating for women living with HIV who are incarcerated (locked up, in prison or jail) can be extremely important to them, their families, and their communities. The obstacles to good health in prison or jail are exacerbated by the obstacles to self-advocacy behind bars. So you have an important role to play if you accept the challenging role of supporting incarcerated women by advocating on their behalf.

The United States has the highest number of people who are incarcerated in the world. As of 2023, there were 565 people (all genders) in prison or jail in the US for every 100,000 US residents. The US also holds a greater percentage of women in correctional facilities than anywhere else in the world: 133 per 100,000 residents. By comparison, in Canada and the United Kingdom, 13 of every 100,000 women are in a correctional facility. US women account for 4% of women globally, but more than 30% of women in jail or prison worldwide. Further, nearly one in six US [people of transgender experience](#) — including half of all Black transgender people — has spent time in prison.

It is ... very important that someone who is arrested get their medications quickly, to avoid interrupting their treatment.

In the US, a greater proportion of people in jail or prison are living with HIV than the proportion of people living with HIV in the US population overall. In 2021, about 1.1% of people in correctional facilities were living with HIV, compared to 0.3%-0.4% of people in the general U.S. population. These numbers are even higher in local jails – for example, in 2009-2010, 9% of women who just entered a New York City jail were living with HIV.

Other countries that lock people up at a similar (though still lower) rate compared to the US tend to have authoritarian governments, such as dictatorships; or have rates of violent crime that are many times higher than in the US. The reasons for the high US incarceration rate are a complicated mix of

factors, including harsh sentencing laws, a weak social service network, decades of racist policies and practices in the legal system, and this country's tendency to punish people who are poor. These inequities also contribute to higher rates of HIV for some communities. For more information on the connections between social inequalities and HIV, see our fact sheet on [Why Race Matters: Women and HIV](#).

There are many ways to [be an advocate](#). As with any advocacy work, it is important to listen to the people you want to help. Unless you have been incarcerated yourself or are trying to advocate for a specific woman in prison or jail, it may be more difficult to find out what incarcerated women living with HIV need than if you were surveying your peers at an HIV clinic on the outside, for example. Communications with those for whom you are advocating will most likely be read by prison staff or recorded. Prison rules can be random and difficult to understand, so consulting with the people for whom you are advocating can help ensure that any action you take is helpful. Connecting with prisoner rights organizations either outside or within prisons, as well as with activists who have spent time behind bars, can give you a better understanding of the issues faced by people on the inside -- and a better sense of what you can do to help as an outside advocate.

Click above to view or download this fact sheet as a [PDF slide presentation](#)

The national prison strike in the summer of 2018 was just one recent effort by people in prison themselves to fight for better conditions. It was supported by a number of activists on the outside who held demonstrations and organized other support activities, coordinating as much as possible with the wishes and strategies of the incarcerated strikers. Some of these organizations are listed in the [Relevant Organizations and Articles](#) section at the end of this fact sheet. There are also local/regional groups that deal with facilities in a specific area.

As with HIV activism on the outside, there is a long history of women living with HIV fighting for care, treatment, and rights in US prisons, as well as compassionate release for those who were very sick during the HIV epidemic's early days. For example, in Bedford Hills Correctional Center, New York state's largest women's prison and its only maximum-security prison for women, Katrina Haslip and others who were living with AIDS and were incarcerated in that facility in the late 1980s founded the ACE (AIDS Counseling and Education) Program. This peer-support program became a well-known model for similar groups in other prisons – though resources and staff support for this kind of advocacy continue to vary widely depending on the facility.

In prison, people may be taking a great risk by advocating for their rights: Prison and jail administrations may retaliate against incarcerated advocates, especially when they organize together. One way that outside advocates can help is to take on some of that work by intervening for specific people or groups of people in prison. If you intervene to get someone medical help, you will need a signed release from the person inside that allows you to access their medical information. *Prison Health News* has a step-by-step guide on advocating for the medical needs of people in prison ([page 10 of this document](#)). For more information on the experiences of women protecting their health and advocating for HIV care behind jail or prison walls, see our fact sheet, [Women and HIV in US Prisons or Jails](#).

US Correctional System: The Basics

Depending on their charges (accusations), people may be in a facility that is controlled by the US Bureau of Prisons, or by a state or county Department of Corrections. Federal US law governs all federal prisons, while state law applies only in a particular state, including that state's counties. In addition, rules and regulations determine how exactly a jail or prison is run – for example, how and when someone can request a medical appointment. These rules often differ by county or even facility.

Jails usually house people who are either waiting for their trial or serving a relatively short sentence.

They are operated locally, by a city or county. Prisons are either state or federal facilities in which people are held for longer periods, typically more than a year. Some prisons are operated by private corporations that are paid by the state or federal government. Even privately run facilities are supposed to follow state or federal laws about how people incarcerated there are treated. However, since the operators of such facilities primarily want to make a profit, they do not necessarily follow the rules.

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Immigration detention facilities are the responsibility of the Immigration and Customs Enforcement (ICE) unit of the Department of Homeland Security. These detention centers are often run by private for-profit corporations. People accused of immigration violations – and assumed not to be US citizens – have even fewer rights than people in prison. However, United Nations human rights law and similar international standards still apply – at least in principle, though not always in practice.

Since jails are local facilities, they are governed by local laws and regulations. They may also be geographically closer to a person's family – assuming they were arrested in the city or county where they live. Because of relatively short stays, it may be difficult to get an HIV medication routine set up before the person is already on their way out. You may be able to have the arrested person's medical provider call the facility and insist that their patient needs their HIV drugs. While this is an unusual step, it may well be worth trying in order to avoid a treatment interruption. If you want to advocate with a medical professional on someone else's behalf, you will need that person to give you permission to talk to their health care provider.

The longer sentences in prisons mean that HIV treatment is more likely to be set up and continued. People in state or federal prisons may or may not be detained in their home state. Geographic distance may make it difficult to connect with family and friends or other outside support. The First Step Act, signed into law in late 2018, requires that people be incarcerated within 500 driving miles of their families. However, it applies only to federal facilities, and it will take some time before the changes it makes are put into practice.

Arrest While on HIV Treatment

When a person is arrested, all their belongings – including any medications they may be carrying with them – are taken away by the police or sheriff. The person's HIV drugs may also be at their home, rather than with them.

It is important for a person living with HIV to take HIV drugs as prescribed to avoid potentially severe complications, such as [drug resistance](#) or more [advanced HIV](#). The [US guidelines on HIV treatment](#) recommend that, once started, HIV treatment be continued indefinitely. A large study known as SMART looked at whether HIV drugs should be taken continuously or could be taken as needed. The study began in 2002 and was stopped, several years early, in 2006 because of the higher risk of complications, disease progression, and even death among the group that stopped treatment. It is therefore very important that someone who is arrested get their medications quickly, to avoid interrupting their treatment.

Because of relatively short stays [in jails], it may be difficult to get an HIV medication routine set up before the person is already on their way out.

Some people living with HIV have received harsher sentences for spitting on or biting law enforcement officers, including staff at prisons or jails. The justification for these HIV-related laws and charges usually is that the behavior puts the officer at risk of acquiring HIV. However, the vast majority of cases involve acts that pose either zero risk of [HIV transmission](#), or a risk that is so low that it is basically nonexistent. For example, in 2008, a man living with HIV in Texas received a 35-year sentence for "assault with a deadly weapon" after spitting at a police officer; spit does not transmit HIV. In Kansas, it is illegal for someone living with HIV to "intentionally cause a peace officer to come into contact" with that person's saliva, vomit, mucus, blood, seminal fluid, urine, or feces, when most forms of "contact" with any of these substances during an encounter with an officer would pose no risk. These arrests and laws are rooted in misinformation and bias related to HIV, not science or public safety.

Activists in a number of countries and US states are working to change these discriminatory laws and law enforcement practices, and this worldwide movement has had some successes, including in the US. For example, after two years of work by a Colorado group known as the Mod Squad ("mod" stands for modernization of the laws), led by women living with HIV, the state changed its laws in 2016. HIV is now treated like other sexually transmitted diseases. For more information on how HIV status is used to unfairly punish people, and how this affects women in particular, see our fact sheet on women and [HIV Criminalization and Women](#).

HIV can be transmitted when a person living with HIV is not on treatment and has a detectable [viral load](#) (level of virus in their body) and their blood, semen (cum or pre-cum), and/or vaginal fluids enter another person's body. HIV is not spread through contact with sweat, tears, saliva (spit), feces (poop), or urine (pee).

HIV Testing

When a person is first booked into jail or prison, the facility should evaluate them for medical problems. Depending on the facility, this may include an HIV test. There are four ways this may happen:

- Mandatory: everyone is tested for HIV; you do not have a choice
- Opt-out: everyone is given an HIV test, unless they explicitly say they do not want to be tested
- Opt-in: you are offered an HIV test, but you must explicitly say that you want the test
- On request: no HIV test is offered; you must ask for a test

Most international and US organizations, such as the World Health Organization (WHO) or the US Centers for Disease Control and Prevention (CDC), oppose mandatory HIV testing as a violation of human rights. Just as on the outside, HIV testing is a sensitive issue that requires specific consent by the person to be tested.

In prison or jail, several considerations may come into play when deciding whether to get tested:

- Potential discrimination inside the prison if the test shows that the incarcerated person is living with HIV
- Lack of counseling if the test shows the person is living with HIV
- Need to prove one's HIV status by taking the test (if the person already knows they are living with HIV) in order to get medications
- Testing positive might afford a person access to health care that could otherwise be difficult to obtain.

Being tested for HIV can also be an important step for a person to take in caring for themselves and their health. If they find out they are living with HIV, that is a step toward getting the treatment and care they need. Studies have shown that the earlier a person starts HIV treatment – even if they are not feeling ill – the better their health outcomes later. With today's HIV drugs, people with HIV can, and do, live long, full lives.

Acquiring HIV While in Prison or Jail

In US prisons and jails, the proportion of people living with HIV is higher than the proportion of people living with HIV in the general US population. However, this is not because of high-risk activity happening among incarcerated people. In fact, most people diagnosed with HIV in prison or jail acquired HIV *before* entering the correctional system. For many, prison health care may have been their first opportunity to be tested for HIV.

Because people acquire HIV by doing things that human beings do, and prisons and jails are places where human beings are gathered, it is possible (though not common) to acquire the virus while incarcerated. Just like in the community, people in prison may have sex, inject drugs, or give one another tattoos (there is virtually no risk of HIV transmission through tattooing in a licensed parlor, but the kind of informal tattooing that happens in prisons and jails carries some risk). Prison rules that forbid sex (a basic human activity) and bar prevention methods like condoms and clean needles, make it more difficult for people in prison or jail to make decisions that help them avoid transmission of HIV and [hepatitis C](#).

Some of these laws are slowly changing. In 2016, California became the third state to provide condoms to people in prison – even though consensual sex between incarcerated people remains illegal in the state. Other countries — though not yet the US — have experimented with tattoo rooms or provide syringe exchanges in prisons. Evidence from these programs shows that providing safe injection equipment does not increase drug use but does get more people into substance use treatment.

HIV Treatment in Jail or Prison

Whether a person is held in a federal, state, or county institution, the Eighth Amendment to the US Constitution applies. It reads: "Excessive bail shall not be required, nor excessive fines imposed, *nor cruel and unusual punishments inflicted*." The courts have interpreted this to mean that everyone has a right to medical care while they are in jail or prison. The National Commission on Correctional Healthcare recommends that all facilities keep enough HIV medications on hand to ensure that people just entering the system or transferred from elsewhere continue their HIV drugs. It also recommends access to medical providers who specialize in HIV care.

As with other aspects of life in prison or jail, the reality is sometimes different. A 2007 study estimated that total sales of HIV medications to US correctional facilities were only 29% of what would be needed to treat all people in jail or prison who have been diagnosed with HIV.

Informally, many advocates for incarcerated people (as well as editors for HIV-related publications that are mailed to prisons) report receiving letters from people asking for help getting their HIV drugs when the prison ran out or had the wrong medications. You may encounter this kind of communication as an advocate on behalf of people living with HIV behind bars.

Health Issues Facing Women in Jail or Prison

Access to Menstrual Supplies

Women face additional challenges beyond the issues described above. HIV may affect a woman's [menstrual cycle](#). She may bleed slightly between periods (spotting) or her cycle may become more irregular. The First Step Act requires federal prisons to provide sanitary products, such as tampons or pads, free of charge. However, in many state or county jails, sanitary products are either provided in very limited quantities or not at all. The Dignity for Incarcerated Women Act attempts to change that, but it has not yet become law. Meanwhile, getting sanitary products frequently enough to handle irregular bleeding may be a challenge.

Pregnancy

For [pregnant people](#), the difficulty of accessing HIV drugs after an arrest may not only endanger their own health, but also increase the risk that their baby will be exposed to HIV during birth. Getting prenatal care from a provider familiar with caring for pregnant people living with HIV may be difficult.

The federal Pregnant Women in Custody Act is trying to impose basic standards of care for all incarcerated women during pregnancy and labor, but it has not yet become law. Some prisons or jails do not allow infants born in prison to remain with their birthing parents. A small handful of facilities, however, have nursery or parenting programs that allow infants to stay near the birthing parent for a limited time.

Another concern for women in the US who are pregnant in prison is that they are often restrained with handcuffs or shackles when they leave the prison for medical care, and even while giving birth. Advocates have opposed the inhumane practice of shackling women who are going through the intense experience of labor, pointing out how it harms women as well as their babies. The First Step Act, mentioned above, includes a ban on shackling pregnant women, and some states have enacted laws or regulations prohibiting it. As with other laws affecting prisons, it may be necessary to demand that the law be followed.

Aging

The number of people who are aging behind bars is increasing in the US, and this includes women. In 1991, 3% of the total number of people in prison were 55 years old or older. By 2021, that number had increased to 15% of the prison population. Harsh sentencing and parole practices have led to people remaining in prison into their senior years, and prison systems have not kept pace in meeting the many health needs of aging people.

The health concerns of [growing older](#) have been shown to happen earlier and faster for people living with HIV. The risk of conditions like [bone loss](#) and [heart disease](#) increases for women once they have gone through [menopause](#). In addition to difficulties accessing proper medical care, limited food options in jail or prison make it harder for any woman living with HIV to maintain the kind of healthy, vitamin-rich diet that can help her care for her body. This is especially true for older people.

In recent years, the work of advocates who are currently and formerly incarcerated has brought more public attention to the concerns facing aging people in prison. One message of groups working on this issue, like the New York-based RAPP (Release Aging People in Prison) Campaign, is that keeping people locked up who are elderly or ill does great harm at a great cost, without keeping people on the outside any safer.

Re-Entry Planning for HIV Treatment

Planning for the transition from jail or prison to the outside world is important for many reasons, and continuation of HIV care is just one of them. If people do receive HIV treatment while they are in jail or prison, that care can easily be disrupted once they are released. One study of correctional facilities in Connecticut found that only one in five people returning to the community after incarceration was linked to care within two weeks of release. That proportion increased to 34% at 30 days post-release. The odds of maintaining an undetectable viral load fell the longer it took to get linked to care after leaving a correctional facility.

In 2021, people remained in jail an average of 33 days, with a turnover rate (admissions versus releases) of 42%, the Bureau of Justice Statistics reports. This means most people return to their communities after relatively short stays in a correctional facility. As we discussed above, short stays often mean that HIV treatment is interrupted. They also mean that there is little time for planning a

person's discharge and ensuring that they have a clinic appointment and enough HIV drugs once they leave the facility.

Re-entry planning not only helps formerly incarcerated people maintain their health; it can also reduce the chances that they will return to prison or jail.

Without such steps, those leaving prison or jail are less likely to have an undetectable viral load. Recent research has shown that people with an [undetectable viral load cannot pass HIV on](#) to their sexual partners. Ensuring that incarcerated people living with HIV are treated and linked to care after release has an impact not only on their health, but also on the wider community to which they return.

One program that helps people living with HIV get the care they need once they leave prison or jail is Project Start+. Counselors meet with people two months before they are expected to be released and continue meetings for three months after release. In addition to planning for HIV care, counselors also help their clients plan for meeting other needs, such as housing, an ID, etc. Other programs in California, New York City, Illinois, and Massachusetts, among others, work with local clinics and also help people apply for government benefits, including health insurance. Check with AIDS service organizations in your state to see if any of them can connect you with re-entry planning programs for people living with HIV that might need volunteer support.

Re-entry planning not only helps formerly incarcerated people maintain their health; it can also reduce the chances that they will return to prison or jail. For example, in 2011, 23% of participants in Illinois' Community Reentry Project were subsequently re-arrested, compared to 51% of all prisoners released in the state. Another study showed that being enrolled in Medicaid by the time someone leaves prison or jail reduces the chances that they will return to prison or jail.

Conclusion

In the US, the Eighth Amendment to the Constitution requires that people receive medical care while in prison or jail. This also applies to HIV treatment, but the reality is often different. People who are in jail or prison themselves are most often the ones to win important changes to benefit people who are incarcerated – either through collective action in hunger strikes or work stoppages, or through individual advocacy, including lawsuits. However, as with any other attempts at change, they can use support from others – in this case, advocates on the outside.

Medical care is just one of the things people who are in a correctional institution or have recently left such a facility need. You may need to work with both incarcerated people's rights/prison reform groups and HIV organizations to help make sure that all needs of incarcerated women living with HIV are met.

Relevant Organizations and Articles

Organizations - General

- [HIV Policy Resource Bank: Prisons and Jails \(The Center for HIV Law and Policy\)](#)
- [The Marshall Project](#)
- [Decarceration Project \(The Legal Aid Society\)](#)
- [National Resource Center on Justice Involved Women](#)
- [Prisoner Reentry Network](#)
- [Movement for Family Power](#)
- [Women's Prison Association](#)

Advocacy Campaigns and Interventions

- First Step Act (#FirstStepAct coalition)

- [Release Aging People in Prison \(RAPP\) Campaign](#)
- [Safe and Sound Return Partnership \(AIDS Foundation of Chicago\)](#)
- [Prison Strike 2018 \(Incarcerated Workers Organizing Committee\)](#)

Specific Issues - Resources

- [Caring for Women Impacted by Incarceration \(HIVE; includes video\)](#)
- [Basic Principles for the Treatment of Prisoners \(United Nations Human Rights Commission\)](#)
- [Women's Issues - Prison and Corrections \(Prison Legal News\)](#)
- [Resources \(Prison Activist Resource Center\)](#)

Re-Entry

- [Discharge Planning for People Living With HIV in Correctional Institutions \(TheBody\)](#)
- [Models for Improving Linkage to Care for People Living with HIV Released From Jail or Prison \(National Center for Innovation in HIV Care, PDF\)](#)
- [Release Planning for Successful Reentry: A Guide for Corrections, Service Providers, and Community Groups \(Urban Institute of the Justice Policy Center, PDF\)](#)
- [What Second Chance? The Uncertain Future of Post-Prison Health Care \(The Crime Report\)](#)

Incarceration - General

- [States of Incarceration: The Global Context 2021 \(Prison Policy Initiative\)](#)
- [Yes, U.S. Locks People Up at a Higher Rate Than Any Other Country \(The Washington Post\)](#)

Special thanks to Laura Whitehorn, prison activist, former political prisoner, and past senior editor of POZ Magazine, for her review of this fact sheet.

Additional Resources

Select the links below for additional articles of interest

- [Women's Health Care \(National Commission on Correctional Health Care\)](#)
- [Fighting to Stay Well Behind the Walls \(Positively Aware\)](#)
- [Exhibit in New York Unearths 1990s Activism by HIV-Positive Women in Prison \(Th...](#)
- [In Prison, Women Are 9 Times More Likely to Be HIV-Positive \(The Nation\)](#)
- [Despite Advances on the Outside, Life for Women With HIV in Prison Remains Risk...](#)
- [What's Life Like for Thousands of Incarcerated Women? Imagine if Hollywood's Wo...](#)
- [Growing Up Behind Bars: How 11 States Handle Prison Nurseries \(Cleveland Plain ...](#)
- [Ending Criminalization \(Positive Women's Network - USA\)](#)
- [America's Incarceration Rate Falls to Lowest Level Since 1995 \(Pew Research Cen...](#)
- [People in Jail and Prison in Spring 2021 \(Vera Institute of Justice\)](#)
- [Reflections on Black Women with HIV and Incarceration \(TargetHIV\)](#)
- [To End the HIV Epidemic, Implement Proven HIV Prevention Strategies In The Crim...](#)
- [The Fire Inside: Women Protesting AIDS in Prison since 1980 \(Cambridge Universi...](#)
- [Challenges Faced by Women Living with HIV Who Experience Incarceration \(Centre ...](#)
- [To End the HIV Epidemic, Implement Proven HIV Prevention Strategies](#)



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