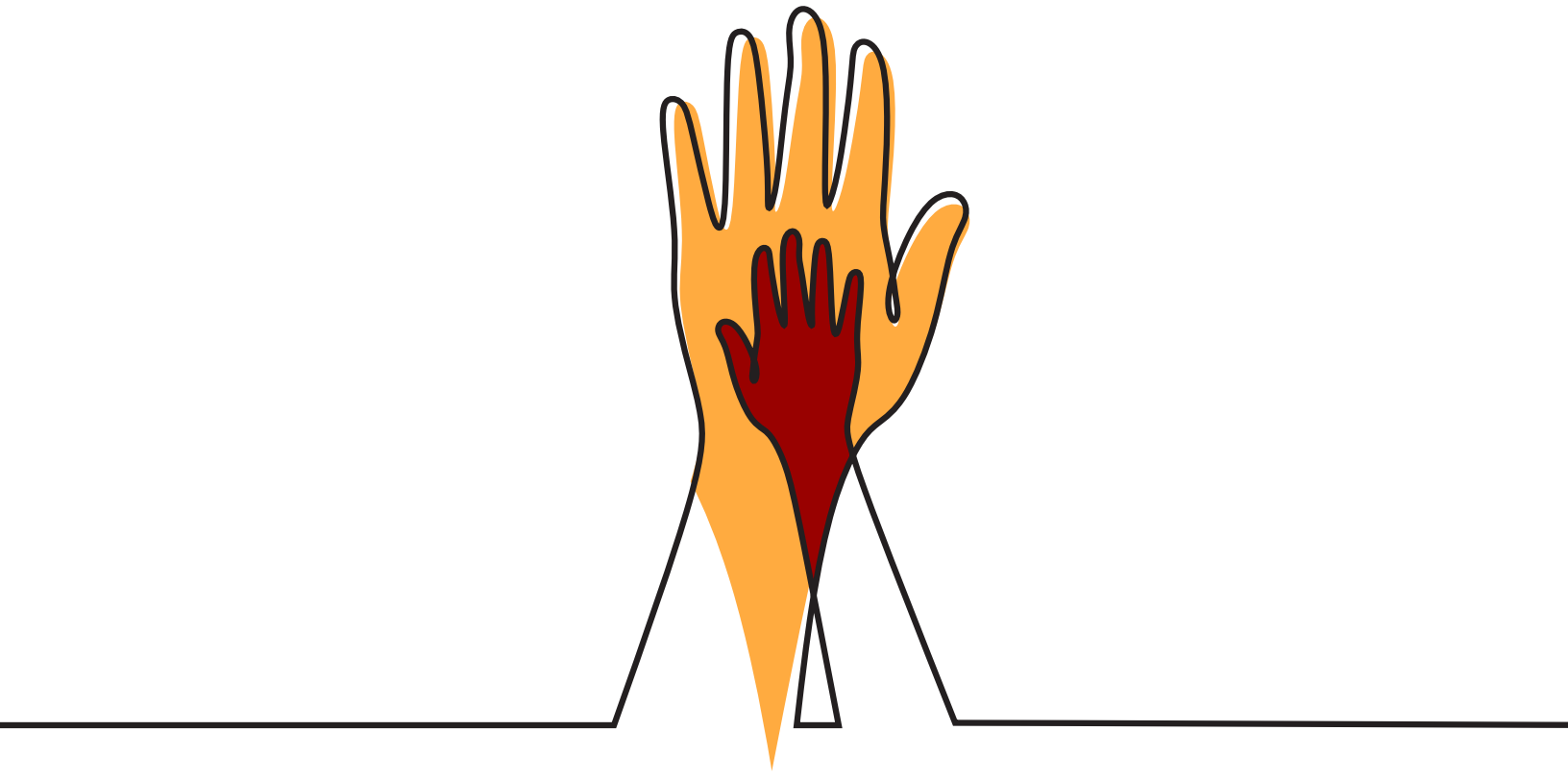
SSC Strengthening Systems of Care for People with HIV & Opioid Use Disorder

SPECIAL PROJECTS OF NATIONAL SIGNIFICANCE

JSI NASTAD

STATE STRATEGIES IN ACTION

PEOPLE FIRST: FOSTERING COLLABORATIVE LANGUAGE AT THE INTERSECTIONS OF HIV, SUBSTANCE USE, AND INCARCERATION



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The HRSA-funded Ryan White HIV/AIDS Program Special Projects of National Significance (SPNS) initiative Strengthening Systems of Care for People with HIV and Opioid Use Disorder (OUD) provides coordinated technical assistance across HIV and behavioral health/substance use service providers. The project aims to enhance system-level coordination and networks of care among Ryan White HIV/AIDS Program recipients and other federal, state, and local entities. The purpose of this initiative is to ensure that people with HIV and OUD have access to care, treatment, and recovery services that are client-centered and culturally responsive.

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This resource is part of the State Strategies into Action series; a compilation of strategies and lessons about a variety of topics related to strengthening systems of care for people with HIV and opioid use disorder (OUD). Each resource responds to common technical assistance (TA) needs identified across states partnering with JSI Research & Training Institute, Inc. as part of the Strengthening Systems of Care for People with HIV and Opioid Use Disorder (SSC) project.

INTRODUCTION

Language is foundational to human experience and directly influences how we think about the world, how we understand ourselves, and how we communicate with and about each other. Unclear language can lead to confusion and inefficiencies, while stigmatizing and prejudicial language leads to harmful practices and dehumanizes people. Establishing a shared language across systems can strengthen our understanding of and care for people who engage with multiple systems at once and who experience marginalization as a result. The need for collaborative language is particularly acute for people with HIV and/or a substance use disorder (SUD) and who have a history of incarceration. The disparities outlined below cause significant morbidity and mortality for communities of color as a result of racist and exclusionary policies and practices across the systems of care and support for HIV and substance use as well as the carceral system. Individuals often engage across systems, which underscores the need for people working in these systems to establish collaborative language.

This document highlights how two states participating in the SSC project are developing collaborative language across HIV, substance use, and carceral systems. Jurisdictions may consider adapting any of the strategies described below to work across systems, foster collaborative language, and support better outcomes for individuals affected by the systems.

A SYNDEMIC: HIV, SUBSTANCE USE, MASS INCARCERATION

Quick Facts

In the United States (U.S.), 2.2 million adults are incarcerated and close to 6.6 million remain under correctional supervision on any day.[1]

Around 1 in 7 people with HIV has contact with the carceral system each year.[2]

Individuals with HIV who have been recently incarcerated are more likely to use emergency department services and to have been hospitalized, and less likely to have achieved viral suppression.[3]

Drug offenses alone account for almost 500,000 persons incarcerated and another 1.15 million people who live within the probation and parole systems for drug-related offenses.[4]

More than half of the individuals in state prisons or those with jail sentences met the criteria for an SUD not related to alcohol or nicotine.[5]

It is important to consider incarceration as a social determinant of health, particularly for communities of color experiencing vast disparities in care and treatment. For a person with HIV and/or a history of substance use, incarceration can cause a harmful interruption in care delivery given a person's immediate loss of contact with their community and support systems. This experience is common because substance use and HIV are criminalized in the U.S.

Human Rights Watch and the ACLU found that enforcement of drug possession laws causes extensive and unjustifiable harm to individuals and communities across the country. The long-term consequences can separate families; exclude people from job opportunities, welfare assistance, public housing, and voting; and expose them to discrimination and stigma for a lifetime. Yet mainstream discussions of criminal justice reform rarely question whether drug use should be criminalized at all.[6]

As of 2021, 35 states still had laws that criminalize HIV exposure.[7] HIV criminalization laws dehumanize people with HIV and directly counter public health efforts to encourage testing and HIV status awareness, thereby putting the lives of people who don't know their status at risk. In an effort to spotlight the harms perpetuated by HIV criminalization laws, the National HIV/AIDS Strategy (2022–2025) calls for the reform of such laws, and February 28, 2022 marked the first inaugural HIV is Not a Crime Awareness Day.

Following incarceration, the danger of re-entry back to community is particularly acute for individuals who use drugs, whose risk of overdose is 12 times higher than the general population.[8] The risks associated with re-entry underscore the importance of recognizing how these systems overlap and linking people to care before re-entry to ensure placement of wrap-around support services and optimal health outcomes.

A SYNDEMIC DRIVER: MULTI-SYSTEM INSTITUTIONAL RACISM

Institutional racism, operationalized by discriminatory policies and practices, connects HIV, substance use, and incarceration. Punitive and carceral approaches to drug use through the 'War on Drugs' have an overwhelmingly disproportionate effect on people of color who use drugs, and intensify the overlapping disparities between race, drug use, HIV status, and incarceration.

Although Black people account for only 12.5% of all people who use substances, they make up close to 30% of all drug-related arrests.[9]

There are roughly five times more white people who use drugs than Black people, but almost 80% of people serving time for a federal drug offense are Black or Hispanic/Latino.[10]

In 2019, Black people made up 13% of the U.S. population, but accounted for 44% of new HIV diagnoses and 40% of all people with HIV in the U.S.[11]

Among people in jail in the U.S., Black men are five times as likely as white men and twice as likely as Hispanic/Latino men to receive an HIV diagnosis.[12]

These disparities have deadly consequences. In 2020, "Black individuals had the largest percentage increase in overdose mortality rates, overtaking the rate among white individuals for the first time since 1999."[13] In addition, 2019 death rates from HIV in the U.S. show that while across all racial and ethnic groups 5.6 individuals per 100,000 died from HIV, these rates were as high as 19.5 per 100,000 for Black individuals and 21.5 per 100,000 for multiracial individuals.[14]

When thinking about and developing cross-system policies and language, keep these racial disparities and their deadly consequences in mind to ensure a race-forward approach that is explicit about addressing race and supporting communities of color.

USING SUPPORTIVE LANGUAGE

Because I am not a status, I am a person and a human being. The labels are usually being used to my disadvantage and dehumanize me. It makes torturing and killing me much easier to do. Just think the next time you see one of us laying dead in the middle of the street and see how easily our deaths are excused by status, label, and history. I believe the current language makes the practice of racism and supremacy appear to be neutral.
-- Dorsey Nunn, for The Marshall Project[15]

The most important step we can take to demonstrate respect is to **listen to how people refer to or identify themselves.** Fostering collaborative language intends to reduce stigma and increase a sense of safety for people living in and moving between these systems. Forcing a particular word or framework that doesn't fit people's way of speaking about themselves directly contradicts the intention of nurturing safety and reducing stigma. So, **listen first!**

Person-first language de-stigmatizes how we talk to and about people because it centers the human, not their diagnosis or other characteristic, and leads with dignity and respect for individuals. While such linguistic changes may seem subtle, they can promote therapeutic relationships while reducing stigma and health disparities.[16]

The substance use, HIV, and carceral systems are updating language to be more person-centered and, in turn, less stigmatizing. Some of this change grew from the studied beneficial outcomes of using person-first language. Adopting person-first language facilitates improved communication; access to and engagement with addiction care; and trust in the health care system.[16] These improvements reduce harm, suffering, morbidity, and mortality.[16] Lastly, person-first language promotes broader social and cultural changes as language changes can shift how we think about people and therefore how we community and interact with people.

The following strategies can be used to develop collaborative language. While you need not use all four, they are strongest when used together.

- **Be aware.** Be conscious of our power to represent (or misrepresent) other people's experiences. Strive to do no harm.
- **Reduce stigma.** Labels used to describe people (e.g., "offender'' "addict") contribute to the stigmatization of already marginalized populations.
- **Consider the whole person**. People are not defined by only one experience or aspect of their identity. Person-first language is humanizing.
- **Respect preference.** Whenever possible, ask people and communities you are working with about the language they use to identify themselves and how they'd like to be identified.

LANGUAGE CONSIDERATIONS

HIV

Since the first years of the HIV epidemic in the U.S., HIV advocates have recognized the power of language. In 1983, a group of advocates who called themselves the People with AIDS Advisory Committee published *The Denver Principles*. This one-page document focused on actions that people with and without HIV could take to support the rights of people with HIV, and the first part of the document (at left) stated the need to clarify and claim language. It states, "[w]e condemn attempts to label us as 'victims,' a term which implies defeat, and we are only occasionally 'patients,' a term which implies passivity, helplessness, and dependence upon the care of others. We are 'People With AIDS.'" Advocates identified early in the epidemic that being defined by an illness immediately resulted in dismissal of the whole person and the whittling down of a person to a medical status.[17]

The Denver Principles (1983)

Statement from the People with AIDS advisory committee

We condemn attempts to label us as "victims," a term which implies defeat, and we are only occasionally "patients," a term which implies passivity, helplessness, and dependence upon the care of others.
We are "People With AIDS."

When talking about HIV or people with HIV, some foundational suggestions based in person-first language can serve as starting points for conversational reorientation:[17]

- **Emphasize the person, not the diagnosis or statistical reference** (i.e., person or people with HIV instead of HIV positive person; number of people receiving an HIV diagnosis instead of number of HIV infections or cases).
- **Diseases—not people—are diagnosed**. This means saying that a person received *an HIV diagnosis* instead of was *diagnosed with HIV*.
- **Avoid the words "infection" and "infected."** Instead, use words like acquired or contracted if talking about HIV transmission. The word "infection" carries the stigma of being contagious, threatening, or unclean, and HIV advocates frequently highlight the consequences of using this word.
- **Keep in mind how HIV works and remember that HIV is not the same as AIDS**. Since AIDS describes a syndrome, not a virus, a person cannot be tested for AIDS nor contract AIDS.[18] Do not use 'HIV/AIDS'; they are not interchangeable, and many people with HIV do not have AIDS. Being clear about language helps us communicate consistently, directly, accurately, and respectfully.

Behaviors associated with HIV can also be talked about in stigmatizing and damaging ways. While the suggestions below are not part of the person-first approach, they prioritize similar values of respect, dignity, and clarity.[17]

- **Stick to facts when talking about sexual health practices**. This includes discussing a person's number of active partners and their practices related to HIV prevention. Do not use the value judging term "promiscuous;" instead, state that they have multiple sexual partners. Similarly, when talking about HIV prevention, avoid saying that somebody engages in "unsafe sex" and instead speak directly about whether or not a person uses condoms and/or pre-exposure prophylaxis.
- **Focus on a person's autonomy**, especially related to managing antiretroviral therapy for people with HIV. Instead of using the word compliant, which implies obeying somebody else's rule, use adherent because that describes a person's participation in self-care.
- **Remove implied blame or fault**, particularly when talking about HIV prevention needs. Given that individuals and communities do not carry inherent risk, say whether a person or community would benefit from prevention services instead of referring to them as high- or at-risk for HIV.

Substance Use

Stigmatizing or discriminatory language to describe individuals who use drugs distorts societal perceptions of their use and potential illness, and prevents them from seeking help and forming strong social bonds. The lack of connection that people who use drugs experience is due to the reality-based fear that opening up about substance use will have a negative impact on their employment and the way in which their neighbors and community view them.[19] Reducing stigmatizing attitudes among law enforcement, clinicians, emergency medical responders, and others who work closely with people who use drugs should be a priority.[19]

It is important to remember that while some individuals who use drugs may self-identify using non-professional terminology *(such as addicts or junkies)*, the role of clinicians, educators, researchers, policymakers, and community and cultural leaders is to de-stigmatize addiction and its treatment, in part by using non-stigmatizing language.[16]

Examples of person-first, non-stigmatizing language:

- Person who uses drugs
- Person who injects drugs
- Person who uses heroin, alcohol, cannabis, etc.
- Person with a substance use disorder (SUD)*
- Person in recovery

Additional language about the system of care related to substance use:

- Substance use/substance misuse
- Currently using substances/in active use
- Opioid Use Disorder (mild, moderate, severe)
    - Moderate Stimulant Use Disorder
    - Mild Cannabis Use Disorder
- Substance Use Treatment
    - Medication:
        - Medication for Opioid Use Disorder (MOUD)
        - Medications for Addiction Treatment (MAT)
        - Medication Assisted Treatment (MAT)
        - Medication Assisted Recovery (MAR)
    - Behavioral Health Treatment
    - Mutual Aid / Mutual Support:
        - Alcoholics Anonymous, Narcotics Anonymous, etc.
- Return to use/recurrence of use
- Positive/Negative Urine Drug Screen
- Sterile/Used needles, works
- Neonatal abstinence syndrome/neonatal opioid withdrawal syndrome.

* While some substance use may be illegal or unhealthy, be sure to limit language about SUDs exclusively to situations where a clinical diagnosis has been made. A use disorder can only be diagnosed by a clinician as determined by a pattern of behavior. Use of a substance does not equate to a use disorder.

Incarceration

One of our first initiatives is to respond to the negative public perception about our population as expressed in the language and concepts used to describe us. When we are not called mad dogs, animals, predators, offenders and other derogatory terms, we are referred to as inmates, convicts, prisoners and felons—all terms devoid of humanness which identify us as "things" rather than as people. These terms are accepted as the "official" language of the media, law enforcement, prison industrial complex and public policy agencies. However, they are no longer acceptable for us and we are asking people to stop using them. — Eddie Ellis, 2007[20]

As the carceral system has begun to recognize the importance of shifting language, there have been some notable changes. From 2009 to 2017, the U.S. Department of Justice stopped using terminology like "felons" and convicts." In 2016, the Pennsylvania and Washington State Department of Corrections took steps to eliminate the use of terms such as "offender" and "felon." In 2019, the San Francisco Board of Supervisors adopted guidelines advocating for person-first language in the context of the carceral system.[20]

Referring to people who come into contact with the carceral system as "offenders," "inmates," or "convicts" causes an individual offense to linger long after it was committed.[21] Such labeling both dehumanizes and stigmatizes, ascribing permanent labels to people based on actions that arguably represent the worst day or days of their lives, rather than who they are as people beyond an event.[21] Person-first language, as in the list below, can decrease stigma and shift perception of individuals who are involved in the carceral system:

- Person in jail.
- Person on parole.
- Person under carceral supervision
- Individual on probation.
- Person with a history of incarceration.
- Person who has experienced incarceration.

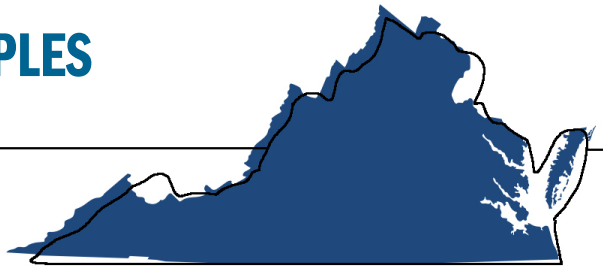
System Terms

An area of language that is important for programs to consider is how to refer to the system of mass incarceration and its partners in the U.S. This resource, while choosing to use the term 'carceral system,' does not recommend the use of one term over another, but provides information about terms commonly used to refer to the system so that organizations can make informed decisions about which to use.

Term	Considerations
Corrections	Used predominantly by the federal government since 1934; provides a broad definition that includes jail, prison, probation, and parole. Infers that the intent or purpose of this system is to "correct" people. Consider that the intent of the system is to punish, and individuals incarcerated as a result of their HIV and/or substance use do not need to be "corrected."
Criminal justice/ justice-involved	The system often does **not** provide justice, particularly to non-white individuals, individuals with HIV, and individuals who use drugs.

Term	Considerations
Prison Industrial Complex (PIC)	Commonly used by prison abolitionists and those who oppose the system of mass incarceration in the U.S. The term is used to "describe the overlapping interests of government and industry that use surveillance, policing, and imprisonment as solutions to economic, social and political problems."[22]
Penal System	A term gaining popularity, particularly in academia. It most generally refers to confinement and punishment, a more accurate reflection of U.S. incarceration, and the ties that the current system maintains to historical penal systems.
Carceral System	A term coming more into the public health and advocacy discourse, means generally "of or relating to jails or prisons."
Criminal Legal System	More people and organizations are using the term "criminal legal system" to describe policing, prosecution, courts, and corrections in the U.S. as an alternative to the 'criminal justice system' due to the reason described above.[23] However, this term provides an indication of criminalization that may not resonate with people who work with individuals incarcerated as a result of their HIV and/or substance use.

STATE EXAMPLES



Virginia

The Virginia Department of Medical Assistance Services is implementing one of the 15 planning grants of the Substance Use Disorder Prevention that Promotes Opioid Recovery and Treatment for Patients and Communities (SUPPORT) Act administered through CMS, SAMHSA, and AHRQ. The purpose of planning grants is to increase the capacity of Medicaid providers to deliver SUD treatment or recovery services through:

- An ongoing assessment of the SUD treatment needs of the state.
- Recruitment, training, and TA for Medicaid providers that offer SUD treatment or recovery services.
- Improved reimbursement for and expansion of the number or treatment capacity of Medicaid providers.

Virginia's planning grant focuses on the following broad goals: 1) needs assessment; 2) strength-based assessment; and 3) activities to expand provider capacity and treatment workforce.

Step 1. Identify a desire and opportunity to take a thoughtful approach to language when working with individuals across the HIV, substance use, and carceral systems.

Staff from the SUPPORT Act Grant team at the Virginia Department of Medical Assistance Services recognized that due to the large-scale and public nature of their project, they had an opportunity to frame language at the intersection of HIV, substance use, and incarceration in a thoughtful manner. Strategic discussions with a TA provider about needs and expectations indicated the need for information, evidence, and resources to:

- Study the etymology of terms such as “justice-involved” and “corrections” to understand their origins; how they carry implicit bias and may affect how people are viewed and served.
- Use person-first language and its evidence base when discussing HIV, substance use, and incarceration.
- Engage partners in the carceral system to thoughtfully update language used across systems.
- Implement a race-forward approach to working across HIV, substance use, and carceral settings recognizing the vast disparities experienced by people of color in these systems.
- Identify terms to refer to the carceral system, recognizing that the SUPPORT Act project and its staff may not want to use common identifiers such as “criminal-justice system” or “corrections.”

Following these discussions, JSI conducted a literature review to develop a TA product that provided information and evidence related to the topics that the Virginia team requested.

Step 2. Use the information and literature gathered to determine shared understanding of language for internal and external purposes.

Upon receipt of the TA product that provided the aforementioned information, the SUPPORT Act Grant team reviewed the information for terminological options. As part of this conversation, the team:

1. Developed a shared understanding of language, its importance, and the various considerations included in this resource.
2. Determined the direction of the language that the team would use internally and externally when discussing the project, its partners, and its participants across systems.

Step 3. Provide education and language setting statewide.

The SUPPORT Act Grant team in Virginia has completed a process that provides a thoughtful foundation of the language its project and partners would like to use moving forward. Due to the public nature of the program, project staff present their approach and identified language at state meetings, on webinars, and throughout their TA activities. This allows the program to be a model for language throughout the state of a dignified and race-forward approach to working across HIV, substance use, and carceral systems.

Partners in Virginia recognize that not everyone will adopt the same language as the program. However, a process of exploration is still valuable to understand the effect of language, especially for people who have been historically marginalized both economically and socially. They note that examining language also supports examining program values and thinking about how to model those values (such as the dignity and worth of individuals) through their behavior.

Massachusetts

The Massachusetts Department of Public Health (MA DPH), Bureau of Infectious Disease & Laboratory Sciences funds service provider organizations to implement the Correctional Linkage to Care (CLTC) Program providing short-term intensive services for individuals transitioning from incarceration to their communities. CLTC links individuals with HIV and/or hepatitis C to medical care and SUD treatment services (if needed). CLTC staff work within carceral and community settings to make medical and other appointments for individuals, arrange transportation, assist with health insurance applications, and refer to harm reduction, syringe, and other support services.

Step 1. Convene CLTC staff in a Community of Practice to discuss language considerations.

In the summer of 2021, CLTC providers convened for three webinars to review the CLTC components and share best practices. Based on the positive feedback about peer-to-peer learning, MA DPH began convening CLTC programs in a community of practice on a quarterly basis. Generally speaking, these sessions lack formal agendas/presentations/objectives, and attendance is optional. One of the sessions focused on discussing language considerations for working across substance use, infectious disease, and carceral systems. JSI was invited to present information related to 'Collaborative Language: the Intersection of HIV, Substance Use, and Incarceration' and engage in discussion with community-based CLTC staff.

Step 2. Discuss feasibility of conscious language shifts in community-based CLTC programs.

During the session, community of practice participants identified the following considerations and strategies for implementing equitable and dignified language across systems.

Consideration	Strategy
The language among carceral system partners can be very different from how SUD and infectious disease systems talk to and about their clients.	CLTC staff can "speak life" when working with clients and be cognizant of setting a tone that does not label individuals. CLTC staff can use this language brief to be cognizant of language when talking with clients.
The program is called "**Correctional** Linkage to Care" due to the use of the term "corrections" broadly throughout MA government. There may be an opportunity to consider that language more thoughtfully.	MA DPH can set the tone of language to be used for all system partners.
Changes with carceral system partners can be difficult because the system is rigid.	The rigidity of the carceral system can be helpful as "top down" orders are often strictly followed. Language change champions in the carceral systems can be extremely valuable.
Clients may use stigmatizing language about themselves or their peers because it is the accepted community rhetoric.	Without correcting or embarrassing clients, CLTC staff can reflect what the client said using non-stigmatizing person-first language.

Step 3. Determine next steps to thoughtfully consider language among system partners engaged in the CLTC programs.

Community of practice participants and facilitators want to continue discussing strategies to use thoughtful language within the program and among system partners. The group identified a first step as using this language brief to examine the title of their program (**Correctional** Linkage to Care). This will likely involve a discussion within MA DPH to ensure a consistent approach to language and agreement with all partners.

CONSIDERATIONS FOR STATE ACTION

To ensure development of a cross-system language that prioritizes a person's dignity and self-worth, states must recognize the unjust and vast disparities that HIV, substance use, and incarceration have on communities of color in the U.S. All work undertaken to improve these systems must consider historic and systemic impacts of racism and work to undo them with an eye towards liberation. This means ensuring that staff and partners have a comprehensive understanding of humanity, dignity, and how systems block or interrupt people's ability to live as the fullest extent of themselves without interruption or barriers.[24] With that in mind, states can take the following steps to develop collaborative language.

Step 1. Think critically about where your organizations and partner agencies are in their language-related journey.

Recognize that language use does not change rapidly and the change may not be a linear process. It requires ongoing systematic and individual commitments to shift perceptions and practices over time. To begin, review organizational policies and procedures to critically examine the language used both internally and externally when talking about the systems of and individuals engaged with HIV, substance use, and incarceration. Identify the necessary colleagues to engage in a conversation about the intentionality of language. Ensure cross-system inclusion from those working in HIV, substance use, and the carceral systems, including decision makers. Also consider engaging individuals with lived experience with HIV, substance use, and the carceral system in these discussions.

Step 2. Identify at least three areas in which your organization can reflect on language to discuss racial disparities and the intersection of HIV, substance use, and incarceration with dignity, honesty, and humility.

Review how racism intersects with HIV, substance use, and incarceration and reflect on which terms most frequently apply to your state's context. This may include identifying names of programs to be reconsidered, updating client data collection forms, examining any previously developed language guides, etc. Be sure to use a race-forward approach and consider how multi-systemic racism is perpetuated across these three systems in your context.

Step 3. Plan at least three steps to facilitate engagement and cross-systems initiatives with HIV, substance use, and carceral system colleagues.

This could mean identifying partners to help make the change possible or highlighting areas of communication that need updating based on the information provided in this resource. Starting questions include:

- What terminology is possibly stigmatizing?
- What could you change to make your setting more person-centered?
- Could you establish a routine meeting with a colleague who works in the HIV, substance use, or carceral systems? Routine meetings can build trust and collaboration among colleagues by developing a space to share perspectives and form a foundation for collaborative language.

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