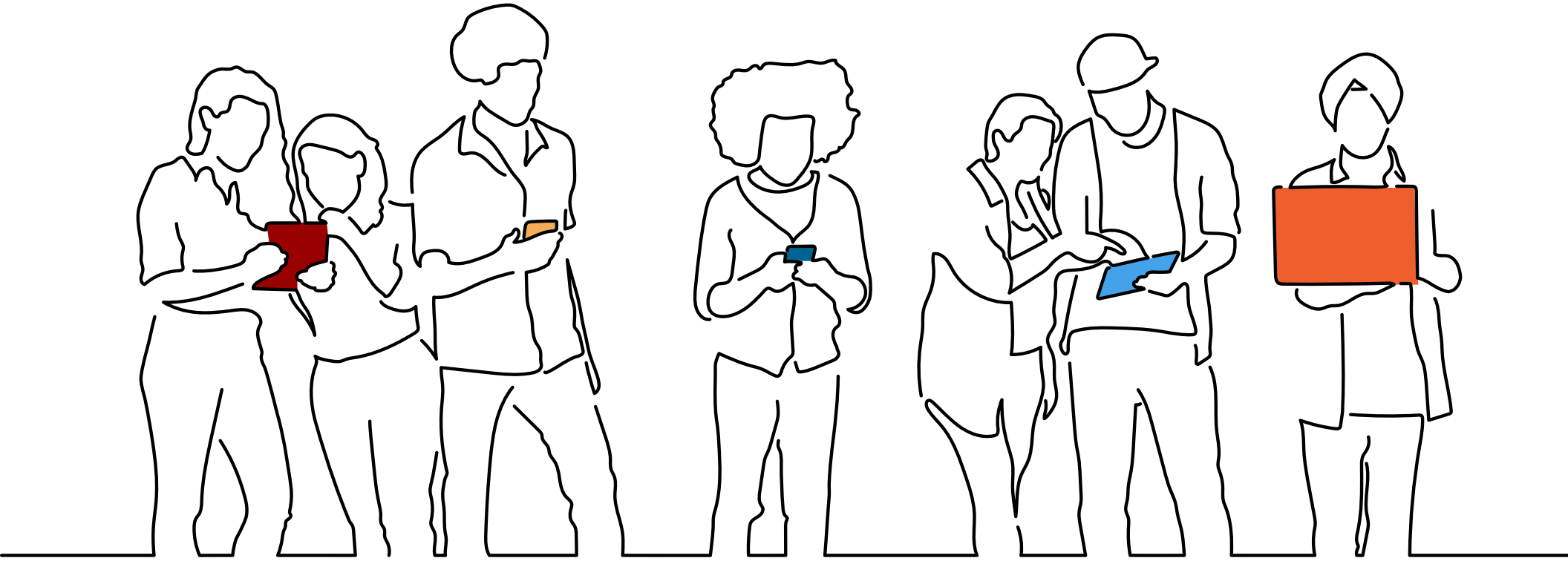
SSC Strengthening Systems of Care for People with HIV & Opioid Use Disorder

RYAN WHITE HIV/AIDS PROGRAM
SPECIAL PROJECTS OF NATIONAL SIGNIFICANCE

JSI NASTAD

INTERRUPTING STIGMA:

A Conceptual Map Depicting Stigma Pathways & Intervening Strategies at the Intersection of HIV and Opioid Use Disorder



The Health Resources and Services Administration (HRSA) Ryan White HIV/AIDS Program Special Projects of National Significance initiative Strengthening Systems of Care for People with HIV and Opioid Use Disorder (SSC) 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 opioid use disorder (OUD) have access to care, treatment, and recovery services that are client-centered and culturally responsive.

SSC developed this resource in response to the needs of the nine state project partners. For more information and additional resources, visit **https://targethiv.org/ta-org/strengthening-systems-care-people-hiv-opioid-use-disorder.**

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INTRODUCTION

Purpose

The Interrupting Stigma: A Conceptual Map Depicting Stigma Pathways & Intervening Strategies at the Intersection of HIV and Opioid Use Disorder was developed by JSI Research & Training Institute, Inc. (JSI) as part of the Health Resources and Services Administration Special Projects of National Significance project, Strengthening Systems of Care for People with HIV and OUD (referred to as 'SSC').[i]

SSC provides coordinated technical assistance across HIV and behavioral health/substance use systems to ensure that people with HIV and opioid use disorder (OUD) have access to client-centered and culturally responsive care, treatment, and recovery services. In 2020, project staff held meetings with each of the nine participating states to identify opportunities to strengthen systems of care across substance use and HIV. A common theme across states was that stigma continues to be a barrier to care for people with HIV and OUD. This resource is intended to help states reduce stigma at organizational and systems levels.

According to the National HIV/AIDS Strategy: 2022-2025 (NHAS), "stigma is an attitude of disapproval and discontent toward a person or group because of the presence of an attribute perceived as undesirable." Stigma and its effects contribute to the syndemic—"a set of linked health conditions that adversely interact with one another and contribute to excess burden of disease in a population,"[2] —of HIV, sexuallytransmitted infections (STIs), viral hepatitis, and substance use disorders (SUD). This document focuses on the role of stigma at the intersection of HIV and OUD systems. Specifically, it illustrates how stigma appears when clients seek care for HIV and OUD, and suggests ways to prevent or reduce stigma. It also directs the audience to resources to reduce stigma at the individual, interpersonal, organizational, and systems-levels within HIV and OUD systems.

Importance of this Tool

Stigma often prevents people from seeking care - whether to prevent disease, treat conditions, or maintain a healthy life.[3] Scholars have illustrated how stigma and discrimination in the health care system produce and maintain inequities and injustices.[4] Discrimination, as defined by NHAS, is "often a consequence of stigma, occurring when unfair and often unlawful actions are taken against people based on their belonging to a particular stigmatized group." On an individual level, stigma is a barrier to housing, employment, health care, and higher socioeconomic status. Stigma can cause individuals to avoid or delay health care and prevent them from disclosing health conditions to their providers. These actions can increase the severity of symptoms and result in higher rates of hospitalization, emergency room visits, and health care-related costs.[5] NHAS aims to decrease stigma among people with HIV by 50% by 2025.

Audience

There are many training resources for HIV and behavioral health provider professional development; fewer exist at the intersection of HIV and OUD, particularly at the systems level. This tool describes the roles, responsibilities, and opportunities for health department leadership, management, and staff, as well as service providers across HIV and OUD service systems, to reduce stigma.

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[i] This tool is adapted from the "Stigma Pathways to Health Outcomes Model" published in the Chief Public Health Officer's Report on the State of Public Health in Canada 2019, Addressing Stigma: Towards a More Inclusive Health System - Canada.ca

How to Use This Tool

The information provided in this tool can support ongoing discussions, strategic planning, needs assessment, policy development, and training as states collaborate across HIV and OUD systems of care. The tool introduces a framework that states can follow in their local planning or training efforts. The tool includes background information and can help staff facilitate conversations about how stigma affects people with HIV and OUD as they seek care and navigate multiple systems. It outlines a framework for identifying opportunities to interrupt stigma by focusing on its causes at multiple levels, beginning with systems. This approach differs from many stigma resources that focus on training for frontline staff and providers and emphasize individual-level interventions. This framework is intended to help states identify opportunities to put policies and practices in place that prevent discrimination and promote access to care across HIV and OUD services.

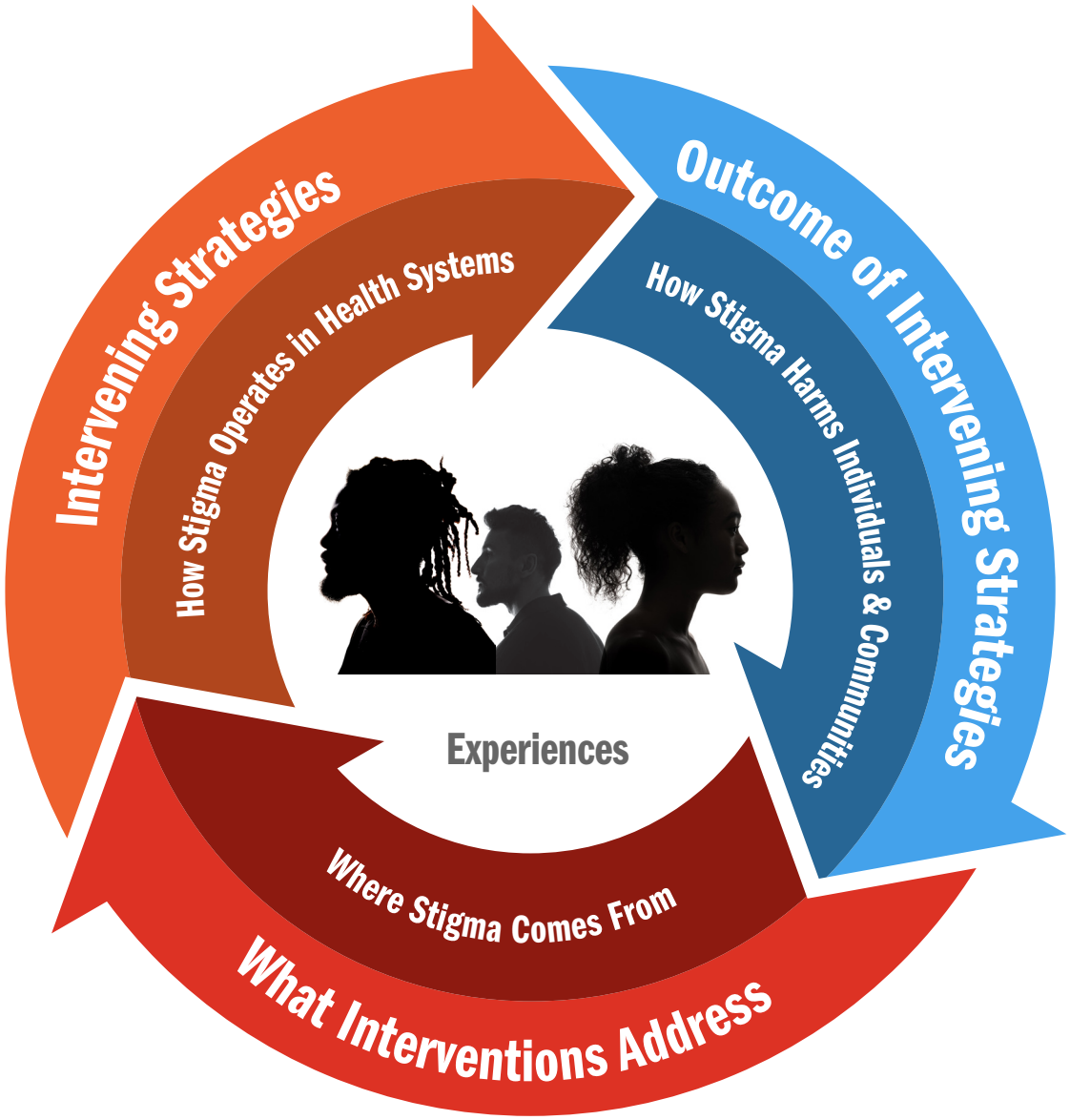
In practice, leaders can use this tool to review their policies, practices, data collection, analysis activities, and training and contracting requirements to identify where they can implement stigma reduction strategies at the systems level. At the organizational level, agencies can: 1) assign the tool as required reading; 2) synthesize and present information to colleagues; 3) lead activities and facilitate discussions that follow its structure; and/or 4) use the content and recommendations to create job aids and other resources. Activities and discussions can be broken up and incorporated into regular meetings, or stand alone as part of longer workshops, strategic planning sessions, and trainings. A best practice is to include staff from both HIV and OUD systems of care in the activities.

Sample discussion-based approach to explore the role of stigma in HIV and OUD systems of care

- Include staff that represent both HIV and OUD programs/services.
- Develop agenda to:
    - Establish a baseline understanding of stigma in the health care setting among participants (see example questions below)
    - Brainstorm opportunities for systems-level interventions for the local context
    - Agree upon next steps
- Pose questions and ask participants to submit individual written responses (via virtual or in-person white board, sticky notes, etc.).
    - Initial questions may include:
        - How have you seen (or heard) stigma show up in the health care system for someone with HIV and OUD?
        - What happens when people with HIV and OUD encounter stigma when they attempt to seek medical care?"
    - Organize similar responses and facilitate a conversation to process the group's input.
    - Following a similar brainstorming approach, ask:
        - What are opportunities to intervene and prevent the negative outcomes the group just described?
        - What would need to happen in your setting to make these changes possible?
    - Organize similar responses and facilitate a conversation to process the group's input.
- Using the tool, highlight the systems-level interventions the group has identified.
- Share the tool and determine if there are opportunities not yet mentioned.
- Facilitate a discussion to identify the challenges to and facilitators of implementation.
- Identify next steps:
    - What are possible next steps?
    - Who needs to be involved?
    - What resources are needed?
    - What is the timeline?
    - Who will be responsible for making sure the activities are completed?

Another option is to share the scenarios in the tool in advance and have a discussion about them before discussing opportunities and personal experiences.

STIGMA PATHWAYS & INTERVENING STRATEGIES AT THE INTERSECTION OF HIV AND OUD[6]



WHERE STIGMA COMES FROM: UNDERLYING FACTORS

Underlying factors, also known as drivers, contribute to stigma in individuals, organizations, communities, and systems. Understanding these root causes, listed below, can help identify interventions to prevent and reduce stigma.

- **Stereotypes/labeling:** Stereotypes are general beliefs, especially wrong beliefs, about groups of people. Labeling is the use of terms that reflect stereotypes, such as "addict" or "convict."

- **Fear:** Stigma often results from fear. For instance, fears about people with HIV and who use substances may include the fear of HIV and other infectious disease transmission; death due to HIV or substance use; unpredictable behavior; an inability to manage their health condition; and the cost of their care.

- **Harmful norms:** Norms are expectations and rules that are socially enforced and guide behavior within a group. Cultural norms related to substance use, gender roles, sexual practices, and peer pressure reinforce stigma. For example, norms related to monogamy may prevent providers from discussing sexual agreements with couples, thus missing opportunities to develop a risk-reduction plan for HIV and sexually transmitted infections.

- **Unequal power dynamics:** People with lived experience are often not in positions of power or part of policy decision-making. A lack of representation in leadership roles and limited opportunities to provide input to and inform agendas reinforce unequal power dynamics.

- **Lack of awareness:** Community members, providers, and clients may not be aware that HIV and OUD are both medical conditions. They may not understand what words are stigmatizing and how stigma affects and harms people.

- **Lack of knowledge/misconceptions:** Community members, clients, and providers may hesitate to admit when they lack knowledge, thus reinforcing misconceptions. Providers may then be unable to manage health conditions or discuss protective factors that decrease risk for HIV, hepatitis C virus (HCV), and overdose with clients.

- **Negative attitudes/beliefs:** Personal, religious, cultural, and other beliefs and attitudes can lead to stigma. People may have personal objections to individual choices and behaviors, such as sexual relationships between individuals of the same sex and substance use that affect how they treat others.

- **Internalized stigma/shame:** Individuals may internalize negative stereotypes and beliefs, which can lead to feelings of shame, fear of disclosure, and isolation. These feelings can keep individuals from seeking testing, care, and support services.[5]

- **Institutionalized procedures, practices, or policies:** A key driver of stigma for people with HIV and who use substances is when stigma is institutionalized in procedures or practices, including in care settings.[6] Such practices include providing care at separate clinics or "flagging" charts to distinguish clients with HIV or OUD from other clients.

TYPES OF STIGMA

This tool focuses on two overarching types of stigma: health-related and societal. Often these intersect, particularly for people with HIV who use substances.

- **Health-related:** These types of stigma pertain to health conditions, such as HIV status, substance use, mental health, viral hepatitis, and other infectious diseases.

- **Societal:** These types of stigma pertain to personal characteristics that are judged by society, including race, ethnicity, language, gender identity, sexual orientation, occupation, geographic location or origin, socioeconomic status, age, migrant status, disability, insurance status, involvement with the criminal justice system, and others.

- **Intersecting stigmas:** People with HIV and those who use substances often experience more than one type of stigma simultaneously, which multiplies the effects on them.

HOW STIGMA OPERATES IN HEALTH SYSTEMS

Stigma appears in health systems in many ways.

- **Stereotyping, demeaning, and dehumanizing language and portrayals:** In the context of HIV, most advocates prefer images that highlight people living healthy and active lives. Similarly, advocates caution against using images of alcohol, syringes, or pills when presenting information about SUD, as these may trigger someone in recovery.[7] Stereotypes about a client's character or profession can be perceived as judgmental and demeaning.

- **Social exclusion:** Unspoken social norms may determine what is acceptable and what is not acceptable. The use of alcohol is, for the most part, socially accepted and may be overlooked by a provider when assessing a client's behaviors. The use of marijuana is less acceptable in some places, especially in states where it is illegal. In comparison, the use of synthetic drugs and opioids is usually socially unacceptable, which may prevent people from seeking and accessing needed services. Similarly, individuals who experience homelessness or who are currently involved with the criminal legal system might experience social exclusion that hinders their efforts to access services.

- **Discriminatory policies, norms, and behaviors:** Health organizations may provide substandard or discriminatory care by failing to immediately prescribe antiretroviral therapy to an individual with newly diagnosed HIV because the provider believes "the person is not ready." If unfair practices of professionals in an institution recur or are tolerated or condoned by organizational leaders, they indicate systems-level stigma.

- **Criminalizing laws and policies:** Laws and policies create structural conditions that disadvantage or penalize people with HIV and people who use substances. These include HIV and STD criminalization laws,[8] laws that criminalize sex work, statewide and federal bans on syringe services programs (SSPs), homeless encampment bans, and more.

- **Hate crimes and assaults:** A hate crime is "motivated by malice toward someone's identity, perceived identity, or affiliation with a specific group. Perpetrators of hate crimes often do not distinguish between gender identity, gender expression, and sexual orientation."[9] Offenders also target individuals due to their race, religion, national origin, citizenship status, class, or employment. In particular, transgender women of color and people who engage in sex work experience high rates of violence.

HOW INDIVIDUALS EXPERIENCE STIGMA

Individuals experience the effects of stigma in a variety of ways. In the health care system, stigma often leads to inequitable care.

- **Discrimination and unfair treatment:** Individuals experience this treatment through various means: people who use drugs may be denied HCV treatment; young gay men of color may not receive information about pre-exposure prophylaxis that is provided to other groups of gay men; and people with HIV may be told they can only book their dental appointment at the end of the day so everything can be thoroughly cleaned and sterilized.

- **Receiving poor-quality care:** People with HIV or who use substances may not receive the same care as others. They may have to wait longer, have their care passed off to junior colleagues, or receive inadequate referrals and follow up.

- **Internalizing negative stereotypes and beliefs:** Individuals may feel shame and despair, fear disclosure, and experience isolation. These feelings can lower their quality of life and affect their ability to take their medications and stay in care. When providers fail to ask specific questions about an individual's thoughts and feelings about living with HIV and/or having a SUD, the client might not be able to disclose barriers that must be removed to increase their ability to achieve healthier outcomes such as viral suppression. Stigma also affects the well-being of the health workforce because health care workers may also be living with stigmatized conditions. They may conceal their own health status from colleagues and be reluctant to access care.

- **Anticipating stigma and discrimination:** When individuals believe that negative reactions, stereotyping, and discrimination are imminent, they may experience higher levels of stress and less social support. They may also be less open about their health concerns and current behaviors with providers, and as a result, are less likely to get the support and services they need.

- **Avoiding health services and resources:** Many people with HIV report that once they leave their HIV care provider or the RWHAP system, they experience increased levels of stigma and discrimination, such as from specialty providers (e.g., OB/GYN, dental) and emergency departments. This keeps many individuals from seeking care for other health issues and support services.

- **Denial of health and other services:** Individuals may experience outright denial of preventive or routine care or treatment, as well as "overshadowing," which occurs when health care practitioners ignore or overlook conditions within people with mental health or substance use challenges.

- **Secondary stigma experienced by family, friends, or caregivers:** Family members, friends, and caregivers of people who have HIV or who use substances may experience judgment, particularly blame for "enabling" behaviors. When people who have HIV or use substances seek services, providers may apply the health-related or societal stigmas to their family, friends, or caregivers.

HOW STIGMA HARMS INDIVIDUALS & COMMUNITIES

The effects of stigma are far-reaching and include:

- **Increased stress and trauma:** Experiences of stigma and discrimination lead to increased stress and trauma, which can increase health challenges for people with HIV and who use substances.

- **Reduced coping responses and behaviors:** Harmful behaviors, such as using substances and having unsafe sex, can serve as unhealthy coping responses, including for those who have HIV and who use substances. Providers may not support clients to develop healthy coping skills.

- **Reduced access to health services and resources:** Stigma at the organizational and systems levels can prevent individuals from seeking supportive services, such as harm reduction programs. Restrictive policies can block SSPs, safe consumption sites, and comprehensive sex education in communities.

- **Reduced quality of health services:** Stigma can diminish providers' efforts to serve people with HIV and those who use substances, leading to lower quality of care. This can cause a lack of trust between providers and clients, who benefit from sharing accurate and detailed information. Clients also benefit from health services that are comprehensive and coordinated. Health systems that work in silos and fail to integrate services can lead to duplication of efforts and gaps in services.

- **Delayed diagnosis and treatment:** The lack of trust in health care systems and providers can cause clients to avoid or delay seeking services. When individuals do engage in services, they may not disclose important health information with providers. This can lead to delays in sharing and receiving important information, diagnoses, and treatment.

- **Increased risk of assault and injury:** Stigma places people with HIV and those who use substances at increased risk of assault and injury, including in community and health care settings.

- **Increased adverse mental and physical health conditions**: Stigma often worsens mental and physical health complications especially among people with HIV and who use substances.

- **Decreased quality of life:** People living in locations with higher levels of systems-level stigma report a lower quality of life, and develop chronic diseases, including diabetes, heart disease, stroke, hypertension, and epilepsy, at an earlier age.[3]

- **Reduced life expectancy:**[3] With these additional factors, people living with HIV and who use substances are at higher risk for overdose, lack of adherence to medications that lead to viral suppression, and reduced life expectancy.

- **Increased social and health inequities:** Social and health inequalities reflect differences in health outcomes. When these differences are related to unfair conditions, they become inequities and can lead to poor health outcomes.

LEVELS OF INTERVENING STRATEGIES

When considering how to prevent and reduce stigma, it is helpful to identify the level(s) at which it is occurring. As indicated in the Socio-Ecological Model, [10] intervening strategies can be employed at four levels of influence: individual, interpersonal, organizational, and systems.

Individual

Underlying Factors Addressed

The individual level focuses on lack of knowledge/awareness, misperceptions, and internalization of stigma and shame.

Intervening Strategies with Individual Clients

- **Support clients to identify and use their power:** Frame each interaction to value the client as a partner. Providers can support individuals through client-centered services, education, and appropriate referrals, and by advocating for client needs. Examples of these activities are providing information to clients on their rights and steps to take to act on violations; helping build resilience through peer support; developing personal social support plans; and building coping skills to manage stress.

Interpersonal

Underlying Factors Addressed

The interpersonal level focuses on the interaction between individuals, including agency staff, clients, and providers. Strategies for stigma reduction at the interpersonal levels focus on drivers such as stereotypes/labeling, fear, lack of awareness, lack of knowledge/misperceptions, and negative attitudes/beliefs. The examples below focus on providers, but **all strategies may apply to all members of the care team and clients**, particularly when clients are involved in agency activities through peer programs, advisory groups, etc.

Intervening Strategies with Service Providers

- **Provide information:** Teach providers about health conditions, care, and treatment from a trauma-informed lens, including strategies to comfortably discuss sex and drug-related behaviors and deliver test results. Provide information on cultural humility, institutional policies and strategies, communication strategies, how stigma appears and its effect on health, and ways to prevent intersectional stigma. Information transfer may take the form of lectures, client or provider panel presentations, discussions, seminars, or videos.

- **Support the use of appropriate and respectful language and communications:** Use accurate, humanizing, person-first language, including clients' pronouns, gender identity, and names, to reduce stigma and help people receive appropriate treatment and support. 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. This strategy supports a whole-person approach to care since it emphasizes a client's humanity above any specific care need. Clinics can hold trainings for providers and staff to identify person-first, inclusive language principles, respectful language, and share resources to stay abreast of evolving terms, in particular those specific to communities being served. For HIV and OUD health systems, it is important that providers have a common understanding of and use respectful language and terms. A resource that can streamline and identify accurate and inclusive terminology can be found here.

- **Create opportunities for skills building and participatory learning:** Provide ongoing opportunities for health care providers and staff to develop skills to communicate and work with diverse communities and individuals through training, workshops, and team exercises. When people draw on their own experience and skills to solve problems, they are better able to apply the

new learning and skills to their everyday life and job responsibilities. Case conferences, team discussions focused on attitudes and beliefs, role-plays in which participants get to apply new communication skills, cross-training, and clinical clerkship all support participatory learning.

- **Cultivate relationships with clients:** Invite people with lived experience to design and shape activities, share their perspective and recommendations, help develop empathy among staff, and eliminate stereotypes. Co-designed activities may include panel presentations, testimonials, advisory group meetings, seminar discussions, and video or face-to-face presentations. Consider inviting people with HIV, transgender individuals, young people, racial and ethnic minorities, people who use substances, people who engage in sex work, and individuals with experience with the criminal legal system and homelessness.

Organizational

Underlying Factors Addressed

The organizational level focuses on labeling/stereotypes; unequal power dynamics; harmful norms; and stigmatizing institutionalized procedures, practices, and policies.

Intervening Strategies for Clinics, Organizations, and Agencies

- **Integrate inclusive, appropriate, and respectful language and communications:** Ensure all staff are using accurate, humanizing, person-first language, including clients' pronouns, gender identity, and names, to reduce stigma and help people receive appropriate treatment and support. Identify ways to update language in clinic, organization, and agency communications. Review and revise the language and questions on intake forms to ensure they capture sex at birth and name, pronouns, and gender identity. When partnering with other organizations, work to create a common understanding of the importance of inclusive language, and develop common terminology and messaging on HIV and OUD. Create a gender-affirming environment through gender-neutral bathrooms and signs. Ensure communications are accessible and adhere to Section 508 standards by providing translation, visuals, examples, and appropriate reading levels. Clinics can hold trainings for providers and staff to identify inclusive language principles, respectful language, and resources to stay current on new terms, in particular those specific to communities being served. A resource that can streamline and identify accurate and inclusive terminology can be found here.

- **Conduct collaborative and inclusive assessments and evaluations:** Provide opportunities for clients and their friends, family, and caregivers to provide insight into how stigma and discrimination appear in interactions with staff and at the organizational level, especially in cases where referrals are being made across HIV and behavioral health systems. Conduct ongoing assessments, such as client satisfaction surveys and focus groups. Also use methods that allow clients to provide information confidentially or anonymously about experiences of stigma and discrimination in the organization. Use the information to conduct quality improvement for services provided to people with HIV and who use substances.[11]

- **Conduct community engagement and client advocacy to identify priorities and develop programs and services:** Develop relationships with people who have experienced stigma and discrimination pertaining to HIV and substance use, and involve them in the design, development, and evaluation of programs and policies. Incorporate feedback from community advisory groups, review boards, and planning councils/groups. Develop and implement stigma-reduction interventions. Provide leadership opportunities for people with HIV and who use substances.

- **Develop and implement organizational policies for protection against discrimination and access to justice:** Assess which organizational policies

can be strengthened to eliminate stigma and discrimination among health care staff and workers. Develop value statements across the organization on client-centered care, use of respectful language, and staff conduct. Review demographic and service data to monitor the different experiences of groups most likely to experience stigma.4 Develop and implement hiring policies that value diverse lived experiences in addition to or in place of a formal degree.

- **Implement trauma-informed practices:**[12] Educate staff and providers about trauma-informed principles and approaches. Integrate practices into current services, and develop services that align with trauma-informed care. For example, add trauma-related topics to agency newsletters, board meetings, trainings, conferences, and standing agenda items. Add questions about trauma to needs assessments. Train staff and providers on trauma and resiliency. Review organizational policies and procedures for opportunities to include trauma-informed approaches for providers.

- **Offer integrated, comprehensive, and coordinated services:** Identify services that would benefit from more coordination, such as integrating HIV care and substance use treatment into primary care; providing integrated HIV and gender-affirming health care; and providing mental health care, addiction treatment, harm reduction services, and access to housing and financial support in the same location as other health care services (e.g., primary care, HIV care).

- **Deliver client-centered, equitable, accessible, informed, and respectful services:** Identify opportunities to deliver services that improve the client experience. Ensure accessible services by adding translators, navigators, and peer advocates to care teams, and offering non-traditional hours of operation to accommodate more people. Improve the physical environment of the clinic, such as creating calming and welcoming spaces through bright colors, soothing lights, art, and comfortable furniture. Incorporate questions on intake forms and in health screening and assessments that ask about gender identity and pronouns, use of spiritual and cultural practices, and preferred name. Integrate a trauma-informed and recovery-friendly approach in all aspects of clinic operations and among all staff (e.g., front desk, scheduling, administrative, janitorial). Establish comprehensive partnerships to facilitate referrals for prevention, care, and treatment services (e.g., substance use, OUD, mental health, HIV, sexual and reproductive health) that are not delivered in the facility.

Systems

Research, tools, and training have primarily focused on the individual and interpersonal levels of stigma. However, there is an increased understanding of the systems-level conditions, norms, and institutional policies that contribute to stigma and limit opportunities, resources, and the wellbeing of communities.[6] While the effects on client outcomes may not always be immediately apparent, there is stigma in health departments, primary care networks, Ryan White HIV/AIDS programs, and behavioral health care networks.

Underlying Factors Addressed

The systems level focuses on drivers including labeling/stereotypes; unequal power dynamics; harmful norms; and stigmatizing institutionalized procedures, practices, and policies.[14]

Intervening Strategies for Systems-Level Leadership, including Health Departments including Health Departments

- **Assess stigma and discrimination in health systems and develop action plans in response:** Conduct a broad needs assessment that identifies stigma and discriminatory practices in the health system. Develop action plans for

policies and practices across the system to obtain stakeholder input, conduct quality improvement, assess language and communications, and monitor and evaluate services. Implement a requirement for collecting feedback and input from staff, providers, and clients on experiences of stigma and discrimination. Develop policy statements that promote and institute the use of comprehensive, positive, and non-stigmatizing language, such acknowledging SUDs and addiction as treatable health conditions and eliminating language that solely promotes abstinence-based treatment options.

- **Assess and develop statewide policies that prevent and mitigate discrimination:** Conduct assessments to identify statewide policies that enable discrimination against people with HIV and who use substances. Provide information about these policies, including those that pertain to harm reduction, abstinence, and recovery. Increase awareness of scientifically-based policies and effective public health strategies. Share how policies that are not evidence-based (e.g., policies that require sobriety or medication adherence to access services such as for HIV or HCV treatment) reinforce stigma. Review state civil rights, criminal laws, and law enforcement practices to identify those that criminalize behaviors related to HIV transmission and substance use. Identify policies, such as those that pertain to transgender rights that could be enacted to provide protection from discrimination. Assess opportunities to update reimbursement requirements, such as policies related to peer recovery services, case management, and integrated HIV and behavioral health care in primary care settings. For example, state-level departments can include language in their standards of service declaring their commitment to trauma-informed services. They can then describe specific strategies and practices in policy and procedure documents.

- **Develop inclusive and equitable partnerships:** Develop systems for statewide and multi-sector partnerships and referrals that can improve social determinants of health, such as legal services, housing, employment services, and others that support retention in care. Fill gaps by increasing services and referral partnerships to improve prevention, care, and treatment for substance use, OUD, mental health, HIV, and sexual and reproductive health. Conduct peer sharing sessions to identify strategies that have worked for other states' health departments and systems. Develop shared values and priorities across HIV and OUD systems on client-centered care, respectful language, and conduct. Develop messaging across HIV and OUD systems and services that challenge stereotypes and harmful norms, such as by framing addiction as a treatable health condition rather than a personal failing.

- **Implement standardized requirements and priorities that promote stigma reduction in jurisdictional/organizational contracts:** Set requirements for contractors that support stigma reduction. For example, include requirements for routine training on topics such as trauma-informed care, implicit bias, and cultural humility. Require data by race, sex, gender, and other measures to help identify disparities and discrimination. Include criteria in funding applications to benefit facilities that: 1) provide accessible services and environment through translators, navigators, peer advocates, non-traditional hours of operation, and accommodations for child care; 2) provide integrated, client-centered, trauma-informed, and gender-affirming services and referrals; 3) incorporate minimum standards for assessing clients' support service needs; 4) have internal policies to protect clients from stigma and discrimination among health care staff and workers; and 5) have respectful and inclusive language on intake forms, signage, screening, and in other communications. Incorporate peer review in the grant-making process and create opportunities for advisory groups to provide input on applications. Following awards, promote peer sharing and learning opportunities to overcome stigma. Add contracting requirements for professional licensing, certifications, and training that incorporate stigma-reducing activities. Adapt and promote occupational

safety standards, such as codes of practice and universal precautions, across HIV and OUD systems to decrease stigmatizing activities within health facilities.

- **Incorporate community engagement and advocacy in policies and systems:** Identify structures for community input to ensure respectful and appropriate services. For example, HIV planning bodies and advisory boards can review service standards and help identify stigma reduction interventions. Set requirements for demographics and personal experience for board members, staff members, advisory councils, and other stakeholder groups. Identify opportunities to implement peer-based service delivery and call upon advocate and group member experience to develop services, programs, priorities, and stigma interventions.

- **Integrate and coordinate services across HIV and OUD systems:** Assess relationships and collaboration processes to eliminate obstacles and discrimination for clients who have to navigate HIV and OUD providers and systems. Determine the level of integration that will best use the expertise of HIV and SUD service providers and enhance client outcomes. Identify opportunities to improve care coordination and services by combining funding across HIV and OUD programs to support integrated service delivery (e.g., jointly funding SSP staff positions and supplies). Conduct routine HIV testing and SUD screening in primary care and specialty settings. Offer other integrated care and support services in a variety of settings.

INTERVENTION OUTCOMES

Outcome of Intervening Strategies

Implementing interventions at multiple levels can support positive outcomes as described below.

- **Reduced stigma pertaining to multiple health conditions and societal stigmas:** Intervening strategies can reduce stigma related to health conditions, other personal characteristics, and intersecting stigmas, which affect many people with HIV and who use substances.[17]

- **Strengthened delivery of high-quality, equitable care:** Assessing systems and organizations for high-quality client-centered care can strengthen the delivery of all services, not just those for people with HIV and who use substances.[18]

- **Increased use of health services:** The use of these intervening strategies can help organizations build trusting relationships with people with HIV and who use substances, and develop a reputation for providing high-quality services. Positive experiences can increase use of health services, benefiting individuals, organizations, and systems.[19]

- **Improved health status of all community members:** : With reduced stigma and increased quality and use of services, not only will the health status of people with HIV and those who use substances improve, that of their communities will too.[20]

- **Increased quality of life:** Reduced stigma and improved health status increase the quality of life for all community members, particularly those with HIV and who use substances.[21]

- **Increased life expectancy:** People within groups who experience stigma, including those with HIV and those who use substances, have a lower life expectancy. Interrupting the stigma pathways can lead people within these groups to live longer, healthier lives.[22]

- **Decreased social and health inequities:** By implementing these and other intervening strategies, particularly at the organizational and systems levels, states can disrupt the stigma that perpetuates social and health inequities.[23]

SCENARIOS

The three scenarios below illustrate how stigma affects individuals, organizations, and systems. They depict different levels of stigma, followed by suggestions for interventions that are described in the Interrupting Stigma tool. These fictional stories are intended to prompt conversation about ways to interrupt the effects of stigma and, ultimately, improve individuals' and communities' health outcomes. Review the scenarios and consider if similar situations are taking place in your own settings.

Consider the following discussion questions for each scenario:

- **What are the drivers of stigma?**
- **What types of stigma are described?**
- **How is stigma operating in the health system?**
- **How are individuals experiencing stigma?**
- **How does stigma harm individuals and communities?**
- **What strategies could interrupt and prevent further stigma?**

PETE

PETE IS A 44 YEAR-OLD HUSBAND AND FATHER WHO WORKS AS A CONSTRUCTION WORKER IN EVERETT, WA.

Pete is a Black man who has been living with HIV for eight years. Although he has had sexual relationships with men, he is married to a woman, who also has HIV. He is a client of WE CARE, which has a long history of providing Ryan White HIV/AIDS Program (RWHAP) services and has recently shifted to specifically focus on the needs of Black gay, bisexual, and other men who have sex with men. Many of WE CARE's public service announcements, posters, and pamphlets now feature Black men.

Due to an injury he sustained when he was working a construction job, Pete became dependent on Percocet. He has continued to get Percocet by seeing multiple doctors in his area. He has tried to quit but continues to take it regularly, which sometimes interferes with his life and daily functioning. Because of his injury and drug use, Pete has had a hard time keeping a job. Pete's case manager at WE CARE has expressed frustration with him. He once told Pete that if he wants others to continue helping him, Pete needs to get his life together, hold onto a job, and value his wife for putting up with him. He shouldn't want to just turn into another lazy Black man.

Pete's engagement in HIV care has been inconsistent in the years since his injury. He sometimes goes months without medications or doctor visits. The changes in his employment situation also cause financial strain and he is having a hard time paying his bills. He is ashamed that he cannot take care of his family and wants to get his HIV and Percocet use under control; he fears for his health and future.

During Pete's clinic visits, the provider rarely asks about his Percocet use. WE CARE follows the state guidelines and refers clients with behavioral health needs to other providers, but the process is inconsistent and confusing. In addition, on a few occasions when Pete was referred to opioid use disorder (OUD) services for medication for addiction treatment, he had to repeat his story, fill out duplicative paperwork, and provide multiple samples for lab work, which left him feeling frustrated and like he wasted a lot of time.

PETE CONTINUED

Pete's HIV history is well documented with WE CARE, but there is little documentation about referrals to OUD care or efforts to access OUD services. Pete's file states that his phone number has changed multiple times; he has been unresponsive to the attempts to contact him; and has been unreliable in coming to the clinic for lab work.

Stigma Pathways

Drivers of stigma

- Stereotype of Black men being lazy
- Stereotype of people who use drugs (PWUD) being unreliable and not caring about their wellness
- Negative attitudes toward PWUD
- Lack of knowledge about behavioral health conditions
- Internalized stigma/shame
- Institutionalized procedure of referring out and not talking with clients about related health conditions

Types of stigma

- Intersecting:
    - Health-related: HIV status
    - Societal: race, sexual orientation, and insurance status

How stigma operates within health systems:

- Demeaning language by case manager
- Dehumanizing portrayals by staff in case files
- Discriminatory practice of not having a clear and consistent tracking and referral system to OUD and related services

How Pete experiences stigma:

- HIV and OUD care are not coordinated or integrated
- Internalizes negative stereotypes and beliefs about his health and financial situation
- Avoids health services

How stigma harms Pete and the community:

- Reduced access to and quality of health services and resources
- Delayed treatment for his OUD
- Increased stress about uncoordinated process in the OUD referral and care process
- Increased adverse mental and physical health conditions

Organizational-Level Interventions

- **Develop and implement policies and practices that protect against discrimination:** Since WE CARE has recently shifted its focus to engaging Black gay, bisexual, and men who have sex with men, it could conduct and require staff to attend intensive cultural responsiveness training to teach staff to support Black clients, with a specific focus on trauma-informed care.

- **Use inclusive, appropriate, and respectful language and communications:** In addition to training, WE CARE leadership could institutionalize inclusive language by reviewing and revising staff policies and procedures, including for client file documentation.

Systems-Level Interventions

- **Integrate and coordinate services across HIV and OUD systems:** WE CARE could advocate for improved referral systems between the area RWHAP and SUD service providers with its local, state, and federal partners. It could also conduct partner mapping by listing current and potential referral and community partners to identify gaps and opportunities to serve clients better.

ANTHONY

ANTHONY IS A 22-YEAR-OLD COLLEGE STUDENT WHO WORKS AS A BARTENDER.

Anthony has been to residential treatment to get help for his OUD (injecting heroin). When Anthony entered treatment he tested positive for HIV. He hasn't told anyone because he is afraid of what people might think. He never followed up for support or treatment after his diagnosis and is not in care for HIV.

Following methadone treatment for his heroin use, Anthony went to a halfway house and started using other drugs. He was kicked out of the halfway house and didn't qualify for another one because he was not abstinent. Facing homelessness, Anthony convinced his mom to let him live with her and promised he wouldn't use anymore. She got concerned with how much he was partying and thought he was probably using again, so she told him he was no longer welcome in her house. Since then, he's been staying with different friends, a few of whom use heroin, too.

One night at a party, Anthony overdosed and one of his friends used naloxone to revive him. They called an ambulance and his mother. In the emergency room (ER), Anthony overheard the staff talking about him. One said "I'm tired of spending my nights treating these junkies. They are young and dumb. They know naloxone is available so they just get out of control and expect it to save them." Anthony was furious but didn't say anything because he thought they might be right. He confided what he had heard to his mother and she filed a complaint with the hospital.

ANTHONY CONTINUED

Stigma Pathways

Drivers of stigma

- Stereotypes about age and PWUD
- Negative attitudes about PWUD
- Fear about PWUD
- Internalized shame about drug use

Types of stigma

- Intersecting:
    - Health-related: SUD and HIV status
    - Societal: ageism; he is in recovery but still uses substances

How stigma operates within health systems:

- Stereotyping and dehumanizing language at the ER
- Institutionalized failure to train ER workers to work with patients with behavioral health challenges
- Discriminatory policies that require clients to abstain from substance use to be eligible for housing

How Anthony experiences stigma:

- Discrimination and unfair treatment at the ER
- Internalizes stigma about his HIV status and opioid use
- Receives poor-quality care
- Avoids HIV health services and resources

How stigma harms Anthony and the community:

- Reduced quality of health services at the ER where providers do not support harm reduction, discouraging people to seek emergency services
- Reduced access to health services and resources
- Reduced quality of life and increased stress due to unstable housing

Organizational-Level Interventions

- **Develop and implement organizational policies for protection against discrimination and access to justice**: In addition to clinical addictions training for providers, the hospital could implement training for staff at all levels on cultural humility, addiction, recovery, and harm reduction. Increasing empathy and knowledge of working with people with an SUD will lead to better treatment for all people.

- **Conduct community engagement and client advocacy to identify priorities and develop programs and services:** To keep abreast of and prevent SUD-related mishaps, the hospital can work with organizations that serve people with HIV and OUD to learn how it can better serve those clients. It could also invite people with personal HIV and OUD experience onto its community advisory board.

- **Implement standardized requirements and priorities that promote stigma reduction in jurisdictional/organizational contracts:** The halfway house policy of client abstinence may have been stipulated in its contract. Health departments can review their contracts or service standards to understand how they might be contributing to stigma and discrimination that puts people at risk for homelessness and relapse.

- **Offer integrated, comprehensive, and coordinated services:** The hospital could offer integrated peer programs in the ER to link clients to SUD, HIV, and other support services. Additionally, the hospital could train providers to offer medication assisted treatment (MAT). Providers in the ER could then be equipped to offer MAT along with naloxone and referrals to SUD treatment (see this Substance Abuse Mental Health Services Administration's resource for guidance). There was also a missed opportunity to implement opt-out HIV testing in the ER. Had it been available, the staff would have been able to link Anthony to HIV care.

ANTHONY CONTINUED

Systems-Level Interventions

- **Assess stigma and discrimination in health systems and develop action plans in response:** People with HIV and SUD may face stigma and discrimination in many areas of their lives. Clients who are experiencing a drug overdose are generally taken to the closest ER so cannot choose a site that is known to provide high-quality and culturally responsive care for behavioral health. Hospital networks could implement network-wide policies and training to implement culturally-responsive, comprehensive, and coordinated services in emergency settings.

JOLYNE

JOLYNE IS A 27-YEAR-OLD SEX WORKER IN NEWARK, NJ

Jolyne is a transgender woman who has been living with HIV for three years and using methamphetamine for four years. While she takes different part-time jobs, sex work provides the most reliable and substantial income.

Jolyne has been in and out of HIV care due to her substance use, financial challenges, and the poor treatment she's received at health care facilities. Lately, Jolyne has been tired, anxious, and sick with persistent cold symptoms. With encouragement from friends, family members and others in her support systems, Jolyne enrolled in an intensive outpatient substance use treatment program that is housed in an HIV service organization.

While filling out forms during the intake process at the substance use treatment program, Jolyne was confronted with two challenges to her identify: the occupation answer options did not include sex work, and the question about gender identity only included "Male" and "Female." In answering the occupation question, Jolyne selected "other" and wrote in "sex work." She had no idea how to answer the gender identity question. Feeling disrespected, she confronted the receptionist about the limited answers options. The receptionist told Jolyne that he "would go back to his supervisor for an answer," and that Jolyne should "just write down her gender on the line below female."

Behind the scenes, the receptionist asked his supervisor how to "handle" the transgender client; should Jolyne be in the program for men or the program for women? The supervisor confirmed that the agency did not have a protocol in place.

A week later, during the in-person portion of intake, the social worker conducting the process admonished Jolyne for staying out of care for so long and handed her a stack of applications for jobs at local coffee shops, fast-food restaurants, and big-box stores. Although Jolyne confronted the receptionist about the intake forms, she was hesitant to speak up for herself in this one-on-one setting for fear that care would be withheld. She knew that this agency could help her stay in HIV care while working through her SUD, but felt rejected on several levels and wasn't sure how she'd navigate this while trying to abstain from using meth.

JOLYNE CONTINUED

Stigma Pathways

Drivers of stigma

- Stereotypes about sex work as something people only do out of desperation, and lack of awareness of a person's feelings about their sex work
- Lack of awareness about gender identity beyond the binary "male" and "female"
- Lack of knowledge/misperceptions about people who are transgender and those who are sex workers
- Institutionalized procedures, practices, or protocols that do not consider people who are transgender or non-binary

Types of stigma

- Societal: a transgender woman does not fit into pre-existing identity boxes and sex work is not a legitimate way to earn money

How stigma operates in health systems:

- Stereotyping, dehumanizing language in reference to "handling" the transgender client, as if Jolyne's experience at the agency was her fault
- Social exclusion of transgender people in health care as a result of not having protocols that support their inclusion
- Discriminatory policies, norms, and attitudes that leave clients who do not fit into boxes on a form without options

How Jolyne experiences stigma:

- Discrimination and unfair treatment as a transgender client
- Receives poor-quality care since she doesn't fit into the agency's groups
- Anticipating stigma and discrimination contributes to her delay in seeking treatment
- Avoids health services and resources due to past experiences of stigma and discrimination

How stigma harms Jolyne and the community:

- Increased stress and trauma
- Reduced access to health services and resources
- Reduced quality of health services
- Delayed diagnosis and treatment
- Increased adverse mental and physical health conditions
- Decreased quality of life
- Reduced life expectancy
- Increased social and health inequities

Organizational-Level Interventions

- **Use inclusive, appropriate, and respectful language and communications:** The agency could update their intake forms to include gender identities beyond the binary (e.g., transgender, non-binary, gender non-conforming). Additionally, the agency could provide a training about how to use respectful, person-first language for all agency staff.
- **Conduct community engagement and client advocacy to identify priorities and develop programs and services:** To learn about how the agency can more respectfully and effectively serve non-binary or transgender clients or clients who participate in "illicit" work, the agency could develop and share an anonymous client-feedback form that specifically asks how well the services support different gender identities and how responsive staff are to clients with less traditional jobs. Development of a Community Advisory Board could also serve as an opportunity to provide insight.
- **Develop and implement policies and practices that protect against discrimination:** The above recommendations related to offering trainings and gathering client-level feedback support this intervention as well. Further, agency leadership across the HIV and SUD programs could work together to develop protocols that define not only how all clients should be treated, but also what steps clients and staff can take to report discriminatory behavior. This protocol would also need to describe how the agency would investigate and respond to such reports, and would also require staff training to get everybody on the same page.

Systems-Level Interventions

- **Assess stigma and discrimination in health systems and develop action plans in response:** Other agencies with which this agency collaborates could come together to review their referral processes and language to ensure that these communication and service channels are not perpetuating discrimination or stigma. While this agency may take the lead in convening the group of agencies, this would be a system-wide activity and investment.

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