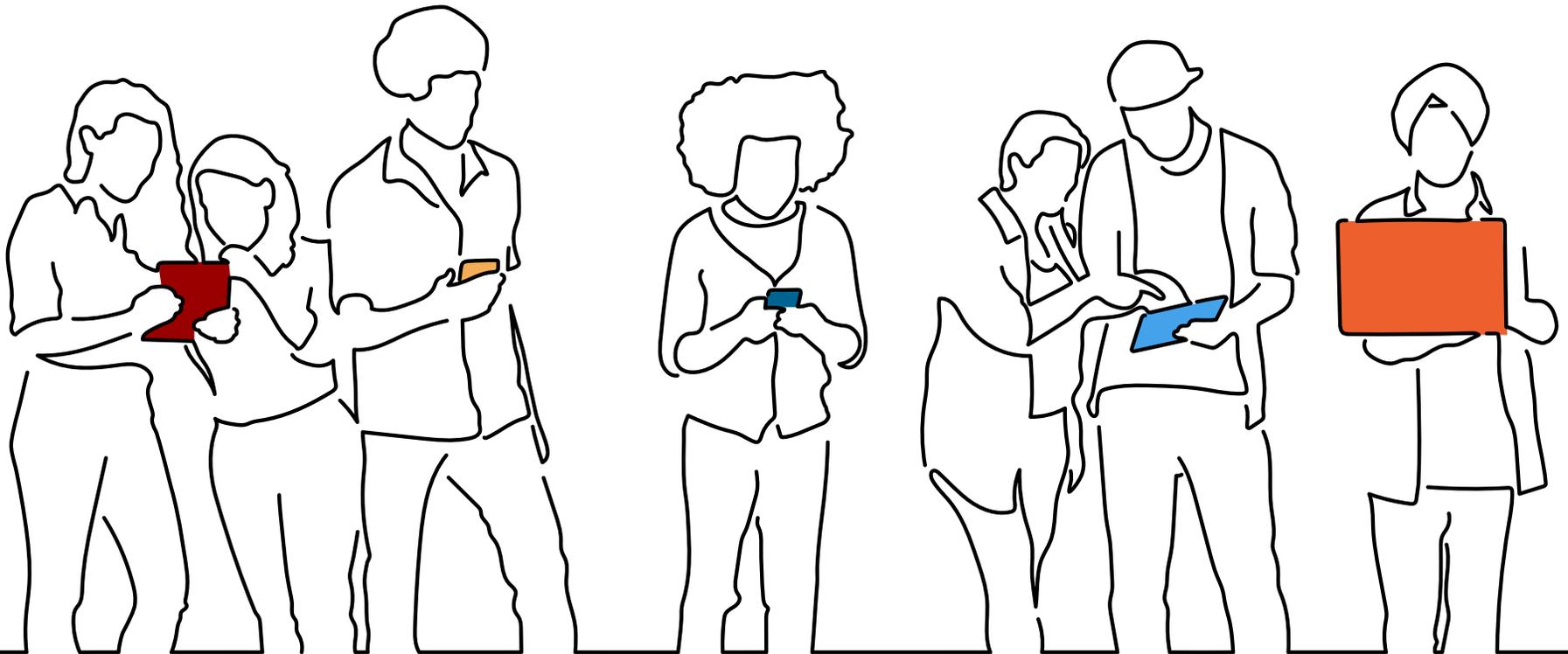


INTERRUPTING STIGMA:

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



The HRSA-funded 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.

This product is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling \$2,095,039 with 100 percentage funded by HRSA/HHS and \$0 amount and 0 percentage funded by nongovernment source(s). The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA/HHS or the U.S. Government.

TABLE OF CONTENTS

Introduction	4
Stigma Pathways and Intervening Strategies at the Intersection of HIV & OUD	6
Where Stigma Comes From: Underlying Factors	7
Types of Stigma	8
How Stigma Operates in Health Systems	9
How Individuals Experience Stigma	10
How Stigma Harms Individuals and Communities	11
Intervening Strategies at the Intersection of HIV & OUD	12
Levels of Intervening Strategies	12
Individual	12
Interpersonal	12
Organizational	13
Systems	15
Intervention Outcomes	17
Scenarios	18
References	25

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-funded Special Projects of National Significance project, Strengthening Systems of Care for People with HIV and OUD (referred to as ‘SSC’).¹ 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, the project 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 optimal health for people with HIV and OUD. This resource is intended to help the states mitigate stigma at organizational and systems levels.

According to the HIV National Strategic Plan for the United States (HIV Plan) published in 2021, “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 syndemics—“a set of linked health problems that interact synergistically and contribute to excess burden of disease in a population,”¹—of HIV and OUD. This document focuses on the role of stigma at the intersection of HIV and OUD systems, and presents opportunities for systems-level interventions. Specifically, it illustrates how stigma manifests when clients seek care for HIV and OUD, and suggests strategies 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 is a barrier to care for people seeking services for disease prevention, treatment of acute or chronic conditions, or support to maintain a healthy quality of life.² Scholars have illustrated how stigma and discrimination in the health care system deprive individuals of their right to accessible, high-quality health care, thus producing and perpetuating inequities and injustices.³ Discrimination, as defined by the HIV Plan, 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.” Discrimination is stigma enacted. On an individual level, stigma is a significant barrier to housing, employment, health care, and increased 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.⁴ The HIV Plan 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.

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

¹ 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

framework that states can follow in their local planning or training efforts by providing background and facilitating 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 targeting 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. Rather, this framework is intended to help states identify opportunities to institutionalize policies and practices that promote access to care across HIV and OUD services and prevent discrimination. Systems-level interventions accelerate implementation of organizational interventions that promote implementation of interpersonal and individual interventions.

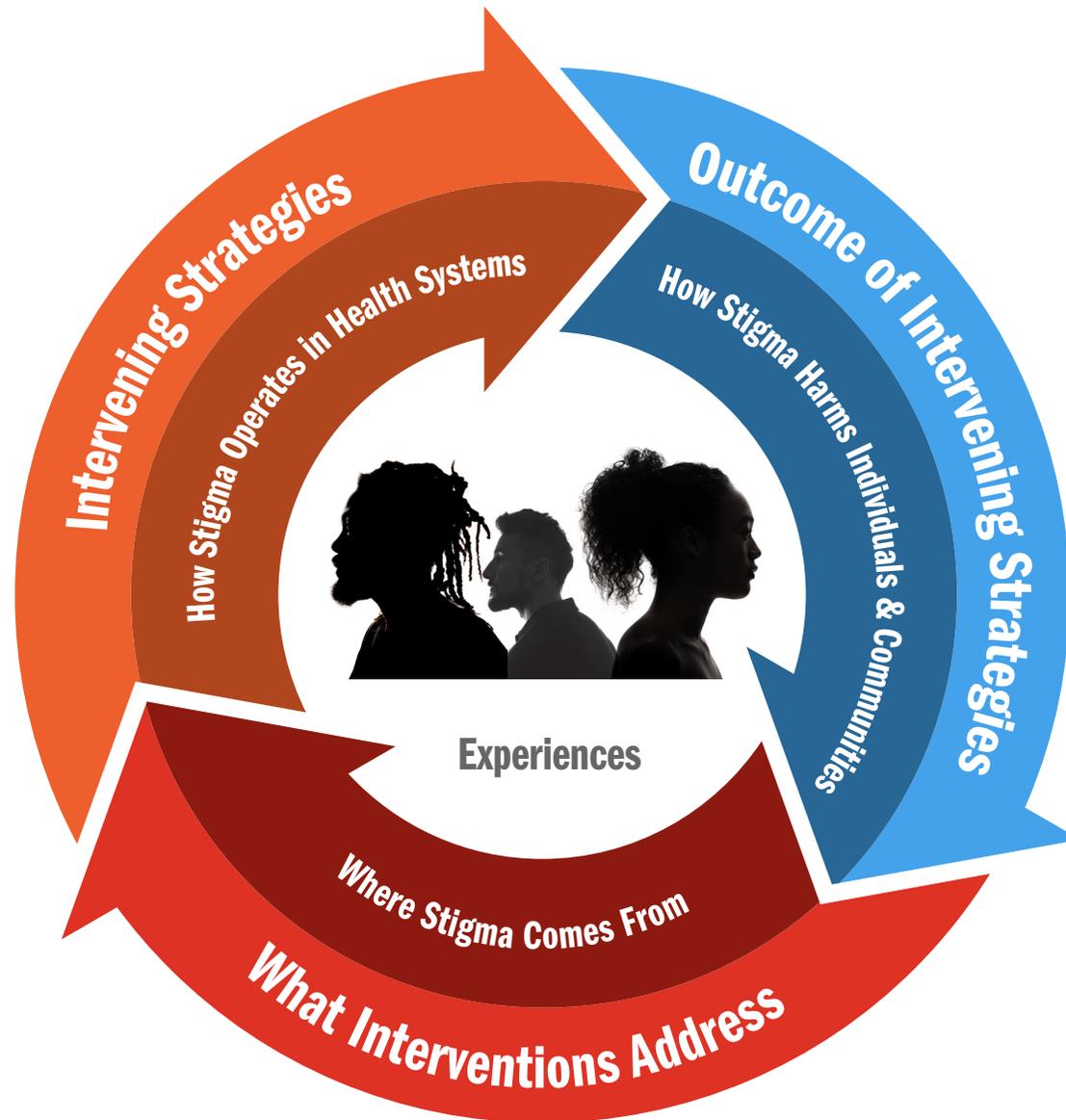
In practice, leaders can use this tool to review their policies, practices, data collection, analysis activities, and training and contracting requirements to identify where they can implement stigma mitigation strategies at the systems level. At the organizational level, agencies can assign the tool as required reading; synthesize and present its information to colleagues; lead activities and facilitate discussions that follow its structure; and/or 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. In all cases, it is essential that discussions take an intersectional approach and include staff from both HIV and OUD systems of care.

Sample discussion-based activity

- Establish baseline understanding among participants (representing both the HIV and OUD systems of care), identify opportunities for appropriate systems-level interventions for the local context, conduct a brainstorming activity, and facilitate a group discussion.

- Pose questions and ask participants to submit written responses (via virtual or in-person white board, sticky notes, etc.).
 - Initial questions related to the conceptual map and scenarios 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 approach, ask: “What are the opportunities to intervene and prevent the outcomes described?” Highlight the systems-level interventions the group has identified.
- Share the conceptual map and scenarios and determine if there are opportunities not yet mentioned.
- Facilitate a discussion to identify the challenges to and facilitators of implementation. Determine who needs to be involved, which resources are needed, which are available, and which steps are necessary.

STIGMA PATHWAYS & INTERVENING STRATEGIES AT THE INTERSECTION OF HIV AND OUD⁶



WHERE STIGMA COMES FROM: UNDERLYING FACTORS

WHERE STIGMA COMES FROM

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

- **Stereotypes/labeling:** Stereotypes are perceived notions about groups of people, including people with HIV and those who use substances. Stereotypes are one dimensional. Labeling is the use of terms that reflect stereotypes, such as “addict” or “convict.”
- **Fear:** Stigma manifests due to fears about people with HIV and who use substances, including the fear of HIV and other infectious disease transmission; mortality associated with HIV and substance use; erratic behavior or unpredictable actions; an inability to manage their health condition; and the economic and/or social ramifications of stigmatized health conditions and identities.
- **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 perpetuate 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 lack awareness of health conditions such as HIV or OUD; stigmatizing language and behaviors pertaining to specific health and social identities; and how stigma manifests and harms people.
- **Lack of knowledge/misconceptions:** Community members, clients, and providers may be reluctant to concede lack of knowledge, thus reinforcing misconceptions. Providers may then be unable to manage health conditions or discuss protective factors that decrease risk for HIV, hepatitis C (HCV), and overdose with clients.
- **Negative attitudes/beliefs:** Personal, religious, cultural, and other beliefs and attitudes can lead to stigma. People may experience moral distress based on personal objection to individual choices and behaviors, such as sexual relationships between individuals of the same sex and substance use.
- **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

- **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 compounds the effects on them.

HOW STIGMA OPERATES IN HEALTH SYSTEMS

Stigma is enacted through practices by people, organizations, and institutions, including within health systems.

- **Stereotyping, demeaning, and dehumanizing language and portrayals:** In the context of HIV, most advocates prefer images that highlight people living vibrantly with HIV to those that show graphic depictions of AIDS symptoms. Similarly, substance use disorder (SUD) advocates caution against using images of alcohol, syringes, or pills, as these may trigger someone in recovery.⁷

Language that focuses on a client's character or profession in the context of HIV and/or SUD can be perceived as judgmental and demeaning.

- **Social exclusion:** The stigma associated with substance use and the unspoken social norms related to what is acceptable and what is not acceptable are polarized. 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 its consumption is illegal. In comparison, the use of synthetic drugs and opioids is usually socially unacceptable, which often prevents people from seeking and accessing needed services. Similarly, individuals who experience homelessness or who are currently involved or recently released from the carceral 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 perpetuate stigma by creating structural conditions that disadvantage or penalize people with HIV and people who use substances. These include HIV and sexually transmitted disease 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 Perpetrators 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 disproportionately higher 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 provision of 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 experience suboptimal care by having to wait longer, having their care passed off to junior colleagues, and receiving inadequate referrals and follow up.
- **Internalizing negative stereotypes and beliefs:** Individuals may feel shame and despair, fear disclosure, and experience isolation. These feelings can keep people from living positively, lowering their quality of life and limiting adherence to treatment and retention 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, 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 Ryan White HIV/AIDS Program (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 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 compound 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 supportive services, such as harm reduction programs. Restrictive policies can block SSPs, safe consumption sites, comprehensive sex education, and more.
- **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 abandonment of 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 devastating delays in receipt of vital information, diagnoses, and treatment among people with HIV and who use substances.
- **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 exacerbates 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 compounding factors, people 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.

INTERVENING STRATEGIES AT THE INTERSECTION OF HIV & OUD

LEVELS OF INTERVENING STRATEGIES

When considering how to prevent and mitigate 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

This 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 advocating for client needs. Examples of these activities are providing information to clients on their rights and steps to take to act on violations; facilitating opportunities to build resilience through peer support and development of personal social support plans; and building adaptive coping skills to manage stressors.

Interpersonal

Underlying Factors Addressed

This level focuses on the interaction between individuals, including agency staff, clients, and providers. Intervening strategies for stigma reduction at the interpersonal levels target 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 other agency staff 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; and intersectional stigma's manifestations and effect on health and ways to prevent or reduce it. 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 and humanizing language, including clients' correct terminology and names, to reduce stigma and help people receive appropriate treatment and support. Clinics can hold trainings for providers and staff to identify 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

INTERVENING STRATEGIES AT THE INTERSECTION OF HIV & OUD

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 in activities to share their perspective and recommendations, help develop empathy among staff, and dispel stereotypes. 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 carceral system and homelessness.

Organizational

Underlying Factors Addressed

This 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 and humanizing language, including clients' correct terminology, pronouns, and names, to reduce stigma and help people receive appropriate treatment and support. Identify ways to integrate respectful language into all clinic, organization, and agency communications. Assess and revise language on intake forms to ensure they capture sex at birth and correct name, pronoun, and gender identity. When partnering with other organizations, work to ensure 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 signage. 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 abreast of evolving 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 manifest in organizations, especially in cases where referrals are being made across HIV and behavioral health systems. Conduct ongoing assessments, such as client satisfaction surveys, using mechanisms for confidential/anonymous discussions on experiences of stigma and discrimination within the organization. Use the information gathered 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 design, development, and evaluation of programs and policies. Incorporate feedback from community advisory groups, patient 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:** Conduct assessments to identify where organizational policies can be strengthened to eliminate internal stigma and

INTERVENING STRATEGIES AT THE INTERSECTION OF HIV & OUD

discrimination among health care staff and workers. Develop unified values across the organization pertaining to client-centered care, respectful language, and conduct. Apply institutional accountability frameworks that focus on stigma reduction by monitoring the accessibility, quality, and/or relevance of health services. This could include breaking down quality improvement data to explore the different experiences of groups most likely to experience stigma, which requires meaningful and respectful collection of patient demographic data.⁴ Develop and implement human resources policies that value lived experience, including but not limited to people and who have experience with the carceral system, homelessness, and substance use.

- **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. For example, Oregon's RWHAP Part B Program used Trauma-informed Oregon's Standards of Practice to complete an assessment and create a work plan. An early outcome was improvement to the AIDS Drug Assistance Program lobby: while most clients receive phone-based services, the few who came to the office were pleased by the reduced clutter, framed artwork, directions to gender-neutral restrooms, and improved lighting.

- **Offer integrated, comprehensive, and coordinated services:** Assess and identify services that would benefit from improvements to 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). When considering service integration, keep the goal of optimal service provision at the forefront, as full integration may not provide the most benefit to clients, given the expertise of the HIV and OUD systems.

- **Deliver client-centered, equitable, accessible, informed, and respectful services:** Identify opportunities to deliver services that enhance client experience. For example, conduct task-shifting, where health care responsibilities are redistributed to other sectors, including through service integration. When HIV care is integrated into primary care, clients become part of the general patient pool and reduce risk of unintentional disclosure. Ensure accessible services by adding translators, navigators, and peer advocates into care teams, and offering non-traditional hours of operation to accommodate more people. Improve the physical environment of the clinic, including changes that facilitate client-centered discussions and decision-making, 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 correct 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. Implement a stigma-reduction popular opinion leader program that focuses on universal precaution procedures, harmful norms and stereotypes, and trauma-informed and client-centered practices.

INTERVENING STRATEGIES AT THE INTERSECTION OF HIV & OUD

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 constrain 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, RWHAP settings, and behavioral health care networks.

Underlying Factors Addressed

This level focuses on drivers¹³ including labeling/stereotypes; unequal power dynamics; harmful norms; and stigmatizing institutionalized procedures, practices, and policies.

Intervening Strategies for Systems-Level Leadership, 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 within the health system. Develop action plans for policies and practices across the system to solicit 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 as 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 discriminatory statewide policies that promote or enable discrimination against people with HIV and who use substances. Provide information about these policies, including those that pertain to harm reduction (e.g., SSPs), abstinence, and recovery. Increase transparency and awareness by sharing information about how policies align with scientifically based and effective public health strategies, and how those that do not (e.g., policies that require sobriety or medication adherence to access services such as for HIV or HCV treatment) perpetuate stigma. Review state civil rights and criminal laws, and identify those that criminalize or discriminate behaviors related to HIV transmission and substance use including law enforcement practices. 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.¹⁴ For example, state-level departments can include language in their standards of service declaring their commitment to trauma-informed services, which can be detailed with specific strategies and practices within 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 session to identify strategies that have worked for other states' health departments and systems. Develop shared values and priorities across

INTERVENING STRATEGIES AT THE INTERSECTION OF HIV & OUD

HIV and OUD systems, pertaining to 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. For example, Iowa's Bureau of HIV, STD, and Hepatitis joined the substance use, nutrition, cancer, tobacco, early childhood development, and refugee health bureaus to convene an interagency trauma-informed workgroup. Additionally, using a mixture of federal, state, and rebate funds, the RWHAP Part B Program hired a full-time trauma-informed care coordinator to support state-wide efforts to align trauma-informed efforts and facilitate the inter-agency workgroup and discussions on implementing trauma-informed care with sub-recipients.

- **Implement standardized requirements and priorities that promote stigma reduction in jurisdictional/organizational contracts:** Set requirements for contracting that support prevention and mitigation of discriminatory practices. For example, include requirements for routine trainings, such as on trauma-informed care; implicit bias; and cultural humility that include the importance of social and cultural influences on clients' health beliefs and behaviors, the effects of these factors at multiple levels of the health care delivery system, and how to prevent or mitigate stigma at these levels. Require data that are disaggregated by race, sex, gender, and other measures to help identify disparities and discrimination. Include eligibility parameters for funding applications to incentivize facilities that: 1) ensure accessibility of services and the physical 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) require language and communication on intake forms, signage, screening, and other communications that is inclusive, appropriate, and respectful. Other contracting processes include requiring applications that align goals

and measures for HIV and OUD, and incorporating peer review in the grant-making process. At a minimum, create opportunities for advisory groups to provide input on applications.¹⁵ Following awards, promote peer sharing and learning opportunities to overcome stigma for all contracted entities. 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. For example, Iowa's RWHAP Part B Program requires all case management providers to complete a trauma-informed training series that is incorporated into agency sub-contracts.

- **Incorporate community engagement and advocacy in policies and systems:** Identify structures in which community representation and advocacy is most needed to ensure respectful and appropriate services. For example, HIV planning bodies and patient review boards can set 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 the relationships, current collaboration processes, and places where stigma may manifest 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.¹⁶ Identify opportunities to improve care coordination and services by and braiding funds across HIV and OUD 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 support services in a variety of settings.

INTERVENTION OUTCOMES

Outcome of Intervening Strategies

Operationalizing interventions at multiple levels can support positive outcomes, described below.

- **Reduced stigma pertaining to multiple health conditions and societal stigmas:** Intervening strategies can reduce stigma related to health conditions and societal characteristics, and in particular, reduce intersecting stigmas, which affect many people with HIV and who use substances.
- **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.
- **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 consequently a reputation for providing high-quality services. Positive experiences can increase use of health services, benefitting individuals, organizations, and systems.
- **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.
- **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.

- **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.
- **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.

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.



● 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 stigmas

- 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 and systems-level interventions

Organizational

- **Develop and implement policies for protection against discrimination and access to justice:** Since WE CARE has recently shifted its focus to engaging Black gay, bisexual, and men who have sex with men, it could conduct intensive cultural responsiveness training to teach staff to support Black clients.
- **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

- **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
- Societal: ageism, in recovery but still uses substances

Types of stigma

Intersecting stigmas

- Health-related: SUD and HIV status
- Societal: ageism, in recovery but not abstinent and still parties

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 around his HIV status
- Receives poor quality of 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 and systems-level interventions

Organizational

- **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.

Systems

- **Assess stigma and discrimination in health systems and develop action plans in response:** 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. Assessing stigma and discrimination and implementing an action plan in response improves the likelihood that an ER will provide such care.

- **Integrate and coordinate services across HIV and OUD systems:** There was 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.

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

Intersecting stigmas

- 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 trans 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 and systems-level interventions

Organizational

- **Use inclusive, appropriate, and respectful language and communications:** The limited gender identity options on the form highlights the agency's lack of consideration for people who are transgender or non-binary. And, while the receptionist wasn't disrespectful to Jolyne, his lack of answers underscore the agency's denial of non-binary experience as legitimate and real.
- **Conduct community engagement and client advocacy to identify priorities and develop programs and services:** Even if Jolyne decides to stay in care at this agency, she will likely not feel supported as a transgender woman given the agency's lack of training on transgender and gender-nonconforming clients. Jolyne's experience underscores a larger lack of community awareness and a resulting absence of programs and services essential to meeting the needs of all potential clients.
- **Develop and implement organizational policies for protection against discrimination and access to justice:** The absence of a protocol to ensure transgender and gender nonconforming clients are acknowledged and welcome leaves the agency and its staff immobilized and focuses attention away from Jolyne's HIV and SUD (the reason she's seeking care) to her gender identity.

Systems

- **Assess stigma and discrimination in health systems and develop action plans in response:** Proactive evaluation or assessment of how a person might experience discrimination when seeking care can minimize possibility of harm by shifting system processes to preventive measures and mitigation if needed. This strategy establishes stigma reduction as a priority and involves routine examination of how a system is or isn't perpetuating stigma.

RESOURCES

¹ U.S. Department of Health and Human Services. (2021). *HIV National Strategic Plan for the United States: A Roadmap to End the Epidemic 2021–2025*.

Washington, D.C. <https://hivgov-prod-v3.s3.amazonaws.com/s3fs-public/HIV-National-Strategic-Plan-2021-2025.pdf>

² Nyblade, L., Stockton, M.A., Giger, K. et al. (2019). *Stigma in health facilities: why it matters and how we can change it*. BMC Med 17, 25. <https://doi.org/10.1186/s12916-019-1256-2>

³ Livingston, J. D. (2020). *Structural stigma in health-care contexts for people with mental health and substance use issues: A literature review*. Ottawa: Mental Health Commission of Canada. https://www.mentalhealthcommission.ca/sites/default/files/2020-07/structural_stigma_in_healthcare_eng.pdf

⁴ Public Health Agency of Canada. (2019). *Addressing Stigma Towards a More Inclusive Health System*. Ottawa: Minister of Health.

⁵ Braun-Gabelman, A. (2016). *The Role of Shame in Opioid Use Disorders*. Provider Clinical Support System. <https://pcssnow.org/resource/the-role-of-shame-in-opioid-use-disorders/>

⁶ Hatzenbuehler M. L. (2016). *Structural stigma: Research evidence and implications for psychological science*. The American psychologist, 71(8), 742–751. <https://doi.org/10.1037/amp0000068>

⁷ National Institute of Allergy and Infectious Diseases. (2020). *NIAID HIV Language Guide*. Washington, D.C. <https://www.hptn.org/sites/default/files/inline-files/NIAID%20HIV%20Language%20Guide%20-%20March%202020.pdf>

⁸ Centers for Disease Control and Prevention. (n.d.). *HIV and STD Criminalization Laws*. U.S. Department of Health & Human Services, Division of HIV/AIDS Prevention, Centers for Disease Control and Prevention, National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention. <https://www.cdc.gov/hiv/policies/law/states/exposure.html>

⁹ National Center for Transgender Equity. (2009). *Respond to Hate Crimes: A Community Resource Manual*. Washington, D.C.

https://transequality.org/sites/default/files/docs/resources/NCTE_Hate_Crimes_Manual.pdf

¹⁰ Centers for Disease Control and Prevention. (n.d.). *The Socio-Ecological Model: A Framework for Prevention*. U.S. Department of Health & Human Services, Centers for Disease Control and Prevention, National Center for Injury Prevention and Control, Division of Violence Prevention. <https://www.cdc.gov/violenceprevention/about/social-ecologicalmodel.html>

¹¹ NIATx. (n.d.). *Easy and Powerful Process Improvement for Behavioral Health*. <https://www.niatx.net/>

¹² NASTAD. (2020). *Trauma-Informed Approaches Toolkit*. <https://www.nastad.org/trauma-informed-approaches>

¹³ Stangl, A.L., Earnshaw, V.A., Logie, C.H. et al. (2019). *The Health Stigma and Discrimination Framework: a global, crosscutting framework to inform research, intervention development, and policy on health-related stigmas*. BMC Med 17, 31. <https://doi.org/10.1186/s12916-019-1271-3>

¹⁴ Substance Abuse and Mental Health Services Administration. (2020). *Prevention and Treatment of HIV Among People Living with Substance Use and/or Mental Disorders* (Publication No. PEP20-06-03-001). National Mental Health and Substance Use Policy Laboratory, Substance Abuse and Mental Health Services Administration. https://store.samhsa.gov/sites/default/files/SAMHSA_Digital_Download/PEP20-06-03-001%20PDF%20508c.pdf

¹⁵ Chan, N., Fischer, P. (2016). *A Checklist of Potential Actions: Incorporating DEI in Your Grant-making Process*. Equity in Philanthropy. <http://www.equityinphilanthropy.org/2016/10/04/dei-grantmaking-checklist/>

¹⁶ Peters, D.H. (2014). *The application of systems thinking in health: why use systems thinking?*. Health Res Policy Sys 12, 51. <https://doi.org/10.1186/1478-4505-12-51>