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

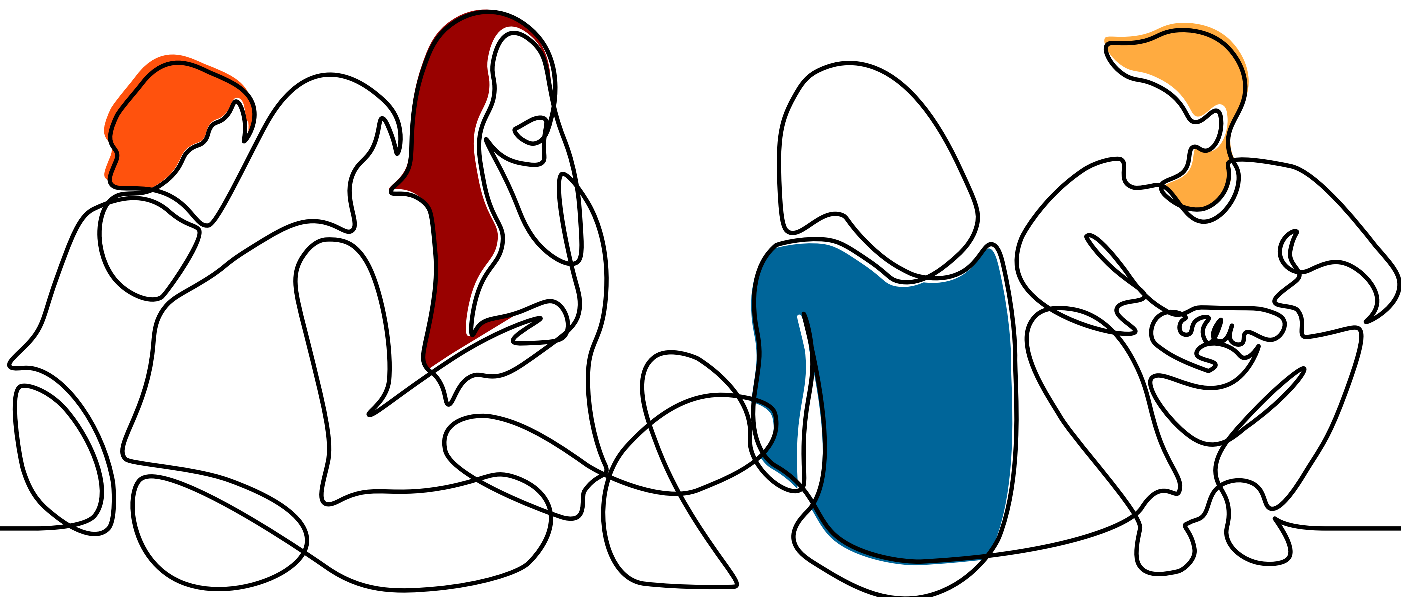
RYAN WHITE HIV/AIDS PROGRAM
SPECIAL PROJECTS OF NATIONAL SIGNIFICANCE

JSI NASTAD

WORDS MATTER:

THE POWER OF LANGUAGE TO STRENGTHEN SERVICES FOR HIV AND SUBSTANCE USE DISORDER

DISCUSSION GUIDE



The Health Resources and Services Administration (HRSA)-funded Ryan White HIV/AIDS Program Special Projects of National Significance (SPNS) initiative Strengthening Systems of Care for People with HIV and Opioid Use Disorder (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 partners participating in the project. For more information about the project and to access additional resources, visit https://ssc.jsi.com/.

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INTRODUCTION

This discussion guide, *Words Matter: The Power of Language to Strengthen Services for HIV and Substance Use Disorder*, is intended to elicit discussions about language, stigma, and discrimination that will strengthen care systems and ensure that people who seek care for HIV and/or substance use disorders (SUDs), including opioid use disorder (OUD), are treated with respect and dignity. The guide includes five discussion packages for use by individuals in state health departments, agencies, and organizations that provide services for HIV and/or SUD, along with instructions and resources to implement the discussions in their meetings.

The discussion packages may be customized to meet the needs of a variety of groups interested in examining the language they use. In particular, the discussion packages included in *Words Matter: The Power of Language to Strengthen Services for HIV and Substance Use Disorder* offer an opportunity to bring together providers and staff who work in two different, but related, fields of health—HIV and SUD—to discuss the language they use about the services they provide and about people with HIV and/or SUD. They are intended to provide a format for participants to discuss language used in HIV and SUD care systems. They can be used with a variety of participants, including people who work within one particular care system.

A designated person should work with HIV and/or SUD program leadership to plan the session and use the instructions and resources in the guide to facilitate them. While special skills or knowledge are not required, facilitation experience will help ensure the process engages and respects people who have a variety of experiences and perspectives. The facilitator is responsible for structuring the discussion session in a way that involves everyone and that ensures democratic decision-making. The guide includes resources for establishing group agreements, which can help the facilitator meet these goals.

Each discussion package encourages use of inclusive and supportive language, free from judgement and that frames HIV and SUD as treatable medical conditions. The implementation of these discussion packages will facilitate understanding and consensus on language as a way to reduce HIV and SUD-related stigma.

Furthermore, the application of the discussion packages may support changes to language and terms that reinforce stigma and undermine trust in health care organizations and systems. Increasing trust in care systems may support greater client engagement and retention in care, ultimately leading to improved health outcomes.

Given that language is continually evolving and being refined, the five discussion package topics can be revisited at some frequency (e.g., annually) to prompt state health departments, agencies, and service organizations to explore the extent to which the language they use is meaningful, appropriate, and inclusive. Use of these discussion packages might result in a list of principles or agreements that could be used to frame organizational and systems language use. It may even result in changes to contracts, leading to new language standards among vendors.

Discussion Packages

A discussion package is made up of short, structured steps intended to be used with a group of people in a meeting format to introduce a topic, facilitate a discussion, and identify small actionable steps to make desired improvements.

THE PURPOSE OF EXAMINING LANGUAGE

Language used to describe systems of care, as well as language that is used within health care settings, can influence access to care and care delivery in multiple ways.[1,2] Terms to define conditions that are treated and clients who use services, and which services are provided can have positive or negative connotations. These connotations, in turn, can influence the way a client is treated, the quality of the care offered, and the way care is delivered. Language can indicate a compassionate or a pejorative approach to clients' health conditions. Language used in care settings can also influence public perceptions of the people being served and the care they receive. Positive public perception can increase acceptance of service sites, including support for expansion, visibility, and accessibility. Furthermore, these perceptions can influence a client's willingness to use services (i.e., a care site that is positively perceived for its mission and the people it serves may increase people's willingness to access its services).

As is true for all language, terms used in care systems and by clients stem from their cultural and historical contexts. Language is continuously evolving to be more person-centered, less discriminatory and stigmatizing, more inclusive, and reflective of a trauma-informed approach. These discussion packages are meant to support participants in thinking through the language they hear and may use, and provide opportunities for shifting language that does not serve the system or the clients optimally.

Stigma can present itself in the language used in care systems, thus contributing to discrimination in the way people are treated and creating an unsafe and unwelcoming care environment.

Stigma is described as irrational or negative attitudes, beliefs, and judgments toward people with particular characteristics, circumstances, or conditions. Manifestations of stigma occur in language and behaviors toward health conditions such as HIV, SUD, and mental illness, as well as non-health conditions such as gender, sexual orientation, ability, ethnicity, and race.

As a result of stigma, people with SUD may feel discouraged from disclosing their drug use with providers (e.g., physician, clinician, case manager); seeking and accessing treatment; and staying in care.

For people with HIV, stigma can discourage individuals from learning their HIV status, seeking and accessing treatment, and staying in care, resulting in suboptimal health statuses.

People with HIV and OUD may face compounded stigma and discrimination related to their health status and other identities, which is an example of intersectionality. Intersectionality is a framework to describe how overlapping social identities (e.g., race, ethnicity, nationality, gender, sexuality, class, disability, health status, employment type and status) contribute to systemic oppression, discrimination, and disadvantage experienced by an individual. However, stigma reduction strategies are often presented in siloes specific to a particular health condition, rather than intersecting health conditions and identities.[3]

Modifying language used about and within HIV and SUD care settings may decrease stigma and discrimination toward clients, ultimately changing how care is provided and how clients experience care and services.

For more on stigma and terms related to HIV and OUD, please go to our other related resources:

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

Glossary of HIV and Opioid Use Disorder Service Systems Terms.

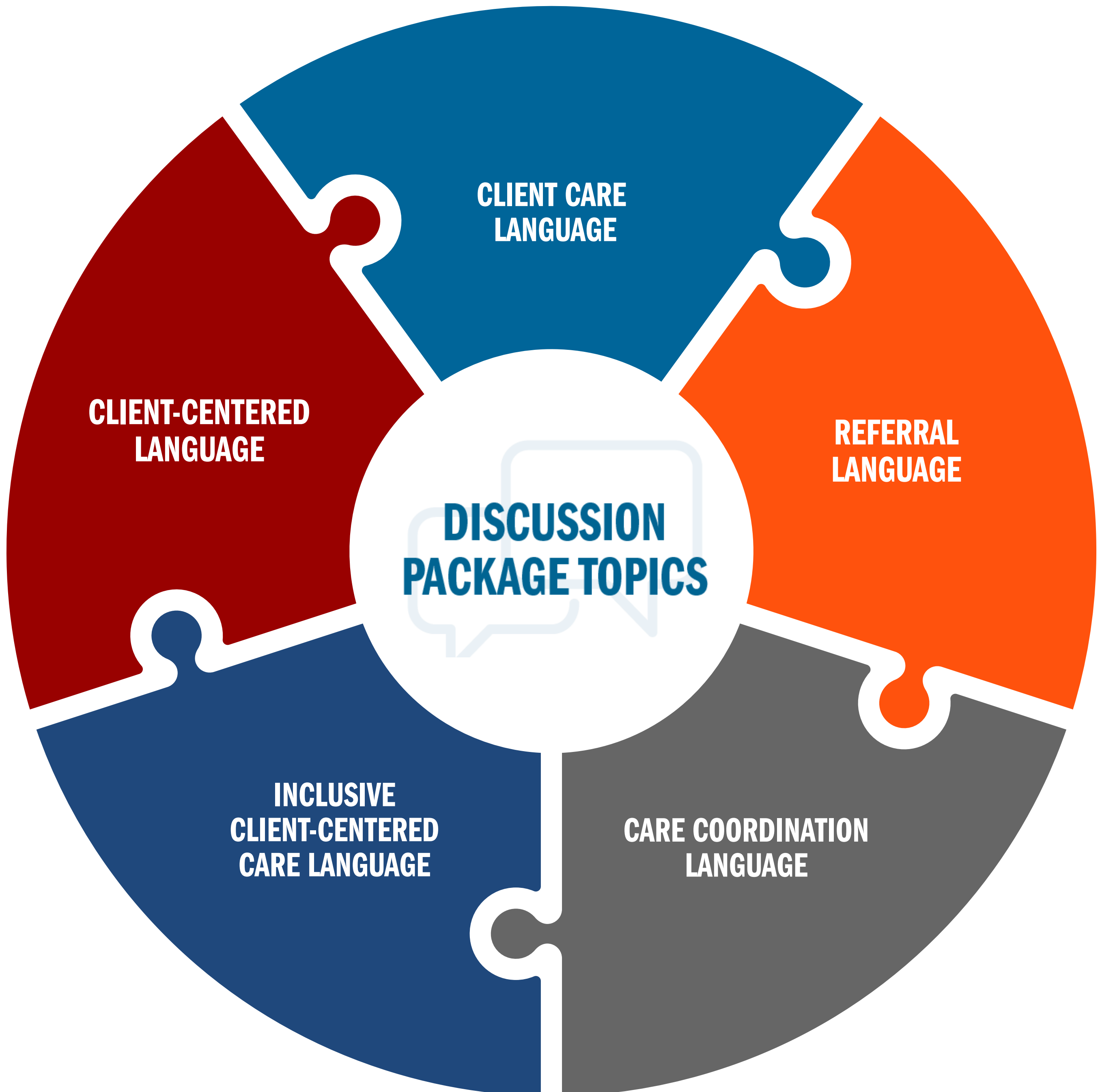
1 National Academies of Sciences, Engineering, and Medicine; Health and Medicine Division; Board on Health Sciences Policy; Committee on Medication-Assisted Treatment for Opioid Use Disorder; Mancher M, Leshner AI, editors. Medications for Opioid Use Disorder Save Lives. Washington (DC): National Academies Press (US); 2019 Mar 30. 5, Barriers to Broader Use of Medications to Treat Opioid Use Disorder. Available from: https://www.ncbi.nlm.nih.gov/books/NBK541389/.

2 The Pew Charitable Trusts. Christine Vestal. Long Stigmatized, Methadone Clinics Multiply in Some States. 2018 October 31. https://www.pewtrusts.org/en/research-and-analysis/blogs/stateline/2018/10/31/long-stigmatized-methadone-clinics-multiply-in-some-states.

3 Stangl, A.L., Earnshaw, V.A., Logie, C.H. et al. 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 (2019). https://link.springer.com/article/10.1186/s12916-019-1271-3

DISCUSSION PACKAGES: IMPLEMENTATION INSTRUCTIONS

The discussion packages are designed to be flexible and adaptable to the context and needs of state health departments, agencies, and service organizations. Activities in this guide can be incorporated into existing meetings or inform new meeting agendas.



The table below lists key steps and related considerations for incorporating a discussion package into a meeting.

STEPS	CONSIDERATIONS FOR THIS STEP
1. Ascertain if there is an existing meeting in which to initiate the discussion package or if a meeting needs to be planned.	• Identify people who may not have had an opportunity to participate in a discussion about language. Consider a mix of participants who can learn from each other. • Identify an existing meeting of this group of people or scheduled one to convene them.
2. Select one of the five topics provided	• Topics can be chosen in any order (i.e., they do not need to follow the order in which they are presented in the guide). One or more topics may be presented in a single meeting. • Consider whether one of the topics is relevant to current events or of particular importance to your group. Questions to consider include: What other topics are planned for the meeting agenda? Is this topic a good fit?
3. Create an agenda	• Consider how much time to allocate to the discussion and any factors that might influence how long to spend on each agenda item in the discussion package. Use the sample agenda as a template and customize it based on what you know about the group's function, familiarity with each other, and familiarity with the topic.
4. Review the discussion package materials and determine which will be sent in advance of the meeting and the timing for sending them.	• Because individuals have diverse learning styles and the topics can be sensitive, let participants know what will be discussed and give them time to review materials in advance of the meeting. Questions to consider include: How much time will the materials take to review based on anticipated familiarity with the topic? What is the usual protocol for receiving meeting materials? What is the best way to tell participants that you will be incorporating a new element into an existing meeting structure?

This guide lists materials and facilitator prompts to introduce topics, engage staff in a discussion, identify action steps to improve the use of language, and give participants additional resources.

A sample 60-minute agenda that can be tailored to each discussion package is provided below. Facilitators can shorten or extend the length of particular agenda items to suit each group's purpose and needs. The discussions are intended for groups of 10 people or fewer. Larger groups may be separated into smaller groups during the discussion.

You will find more details on each agenda item below this table.

AGENDA ITEM	DETAIL	TIMING
Group agreements	Review and confirm group agreements in order to create an environment that is supportive and conducive to honest discussion.	5 minutes
Topic overview	Interest participants in the topic by asking them to view or read the related resource(s), which provide a quick overview of the topic. View one resource or more depending on the time available.	15 minutes
Discussion	Elicit discussion by using the probing questions to have a group discussion to process and apply the topic to the work setting.	20 minutes
Action steps	Use the probes to consider steps to take in order to improve language.	15 minutes
Resources	Spend the last 5 minutes of the meeting providing a preview of the resource list for the topic which will be sent to participants so that they can view in more detail following the meeting.	5 minutes

Group Agreements

As with any group discussion, especially where there may be diverse perspectives, it is important to set group agreements. The facilitator can send a list of suggested group agreements to participants in advance of the meeting and ask them to recommend which to include at the start of the meeting. If the group already has a set of agreements, it can continue to use those and/or add to them. Once participants decide on the group agreements, post them where all can see or refer to them during the meeting. Encourage participants to reinforce/restate the agreements if they are not being upheld.

Conversations on the topics in the discussion packages may become uncomfortable for some based on the topic itself and/or what is said or not said by other participants. Remind participants that they can take a break or step out of the discussion as they need. Provide participants with contact information and/or resources to use after the meeting to address points of disagreement or discomfort.

The following are sample group agreements (Appendix includes a glossary of terms that are included in the group agreements):

1. Be respectful and use respectful language.
2. It is okay to disagree, but don't personalize it. Focus on the idea, not the person.
3. If you talk about people who are not here, don't use their names, unless the situation or experience was of a public nature.
4. Speak for yourself using "I" statements. Don't try to speak for "your group."
5. It's important to discuss topics like race and class.
6. Listening to understand rather than to respond.
7. Acknowledge and identify power differentials.
8. Be curious but not defensive.
9. Strive for anti-racist words and actions at all times.
10. Don't dominate the conversation: let 2–3 people speak before you speak again.
11. Acknowledge micro-aggressions when they occur.
12. Recognize history, acknowledge learned information, and be aware of unconscious bias.
13. Be transparent about decisions without compromising confidentiality of individual experiences that informed the decision.

The facilitator should select relevant materials and send them to participants to review before meeting. Facilitators may make materials optional, strongly encouraged, or required. A variety of materials can be sent to participants in advance of the meeting. The facilitator can determine the appropriate set of materials, which may include:

- The discussion package topic and agenda.
- This guide's "Purpose of Examining Language" section.
- A draft set of group agreements.
- A selection of resources from the "Overview of the Topic" in the discussion package.
- Lists of preferred terms used in participants' programs or agencies that demonstrate respect for people with HIV and/or OUD.

Discussion

Consider designating a timekeeper and note-taker for the discussion (these roles should not preclude those who volunteer for them from participating in the discussion). The note-taker's role is to document action steps only. Discussion participants should be comfortable sharing their reactions, experiences, and ideas, so notes should not be taken during any other portion of the meeting (make sure participants know this).

Ask participants to think about their agency, department, or care setting in reference to what they just read, heard, and/or saw. Remind participants that the purpose of these discussions is to identify where improvements can be made. Encourage participants to think creatively and bring up ideas that could change the status quo.

The facilitator may encourage free discussion or ask people to take turns commenting. Use the discussion probes as they relate to the interests of the group; all probes may not be relevant.

Action Steps

Use the probes to identify languages changes that have the potential to improve client care and experience. Include ideas generated in the discussion to inform action steps.

Help the group keep the action steps realistic and achievable. Small steps are fine! You can ask the group to review the the strategies in Interrupting Stigma for ideas.

Record the action steps, including who will take responsibility, what resources are needed, when it will be initiated, and when it will be completed.

Resources

A list of resources for each topic is provided so that participants can learn more following their participation in the discussion package. Consider adding materials to the resource list that are locally relevant. Preview the resources with participants at the end of the discussion and disseminate the list of resources to the participants after the meeting.

Remember to include resources that support people in having discussions and address feelings of discomfort.

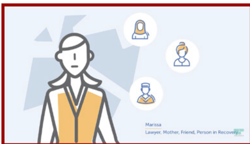
Discussion Package: Client-centered Language

The words used to describe people with HIV and/or SUD have evolved from blaming and shaming to language more aligned with other health conditions. Changes in perceptions and language have been facilitated by individuals, groups, and social contexts; but efforts to improve client-centered language must continue.

Step 1: Review and confirm group agreements

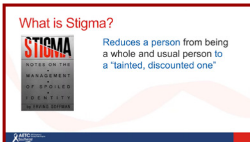
Step 2: Choose one or more resources to view

HIV Stigma: How Far We've Come, How Little We've Gained | TEDxTallahassee (9 minutes)
https://www.youtube.com/watch?v=KmEsACHDHUc
The talk is by a person who was born with HIV and explains that stigma is the real killer.



Words Matter | Shatterproof (2 minutes)
https://youtu.be/5QX17g6Xuk0
Research shows that words shape how people view and treat others. This video offers suggestions for using person-first language to replace the negative, judgmental words that are often used to describe people with SUD.

How do you talk about addiction? Stigma and language | Yale Courses (7.5 minutes)
https://www.youtube.com/watch?v=mCf7jXHYSSI&t=13s
Substance use disorder is one of the most stigmatized medical conditions. This video helps providers begin to destigmatize SUDs by changing the language they use to describe patients, the disease, and the treatments.



How Stigma Leads to Sickness | Southeast AETC (8.5 minutes)
https://www.seaetc.com/cultural-humility-reducing-stigma-discrimination/how-stigma-leads-to-sickness/
This video explains the dimensions of stigma and how it affects health.

Step 3: Discuss as a group

- Reflect on the words used to refer to the people who receive services for HIV and/or SUD within your care system.
    - What are examples of person-first, client-centered language that you frequently hear?
    - What language have you heard used in interpersonal discussions (between providers [e.g., physician, clinician, case manager] and clients, or within care teams) that might be considered stigmatizing?
    - What written language (in medical records, signage, forms, or policies) have you seen that might be considered stigmatizing?
    - What historical terms referring to the people who have received services for HIV and/or SUD need to be updated?
    - How often is person-first language used?
    - Which terms in the following lists are used?

SUD

- https://www.drugabuse.gov/nidamed-medical-health-professionals/health-professions education/words-matter-terms-to-use-avoid-when-talking-about-addiction
- https://www.recoveryanswers.org/addiction-ary/

HIV

- https://www.cdc.gov/stophivtogether/library/stop-hiv-stigma/fact-sheets/cdc-lsht-stigma-factsheet-language-guide.pdf

    - Think about negative linguistic prefixes (e.g., mis-, ab-, non-) that are used in current care system terminology and how could they affect the people who receive services.

- Reflect on the environment in which people receive services for HIV and/or SUD.
    - What language is upheld as appropriate and acceptable?
    - Consider the names of services and signage. Can publicly displayed terminology model appropriate language?
    - What are the expectations that can be made of clients for the use of specific terms describing health conditions and behaviors?

- What terms are used that might make people with HIV and/or OUD feel ashamed, disrespected, or reluctant to speak freely with providers? Consider words that refer to reasons clients may seek care, the frequency of the care they seek, and gaps in care retention.

- Imagine a person with HIV, a person with an SUD, or a person with both who needs services or resources. How might the use of stigmatizing language in care settings and in the community affect that person? Consider their self-image, feelings about their condition, trust in providers and staff, and willingness to access services and remain in care.

Step 4: Document action steps

Document the action steps suggested in response to the questions below in the staff meeting notes/minutes.

How can we ensure that language used with and about clients is inclusive, non-judgmental, and non-discriminatory?

- What steps can we take to raise awareness of the consequences of stigmatizing language and the importance of person-first language? Who needs to be involved in these steps?

- What steps can we take to review and improve the language or terminology used in our written documents, including medical records, client communications, forms, signage, and policies? Who needs to be involved in these steps?

Step 5: Review additional resources

- Stop Talking 'Dirty': Clinicians, Language, and Quality of Care for the Leading Cause of Preventable Death in the United States
  https://www.amjmed.com/article/S0002-9343(14)00770-0/pdf
- Addiction Language Guide
  https://www.shatterproof.org/sites/default/files/2021-02/Stigma-AddictionLanguageGuide-v3.pdf
- Providers Clinical Support System (PCSS) Training. Changing Language to Change Care: Stigma and Substance Use Disorder
  https://learning.pcssnow.org/p/ChangingLanguage#tab-product_tab_overview
- Why Race Matters: Women and HIV
  https://www.thewellproject.org/hiv-information/why-race-matters-women-and-hiv
- Words Matter
  https://www.drugabuse.gov/sites/default/files/nidamed_words_matter_508.pdf
- How to refer to individuals with heroin use disorder: A person-centered perspective
  https://www.recoveryanswers.org/research-post/person-first-language-heroin-use-disorder/
- Stigma in health facilities: why it matters and how we can change it
  https://bmcmedicine.biomedcentral.com/articles/10.1186/s12916-019-1256-2
- Intersectionality and Stigma
  https://www.nastad.org/talking-points-resource-guide-facilitating-stigma-conversations/vignettes
- Resource Guide for Facilitating Stigma Conversations
  https://www.nastad.org/talking-points-resource-guide-facilitating-stigma-conversations/vignettes?page=2
- Our treatment of HIV has advanced. Why hasn't the stigma changed? | Arik Hartmann (video, 17 minutes)
  https://www.youtube.com/watch?v=O13KwsyDqeE
- Shaming the Sick: Substance Use and Stigma | Carolyn Greer | TEDxFortWayne (video clip specific to language from 13:19–14:46)
  https://www.youtube.com/watch?v=eZ0CafocLsY
- Measuring HIV Stigma and Discrimination among Health Facility Staff
  http://www.healthpolicyproject.com/pubs/49_StandardizedBriefQuestionnaireMeasuringSD.pdf
- HIV Stigma Socio Ecological model
  https://whatworksinyouthhiv.org/youth-hiv/hiv-prevention-treatment/stigma

Discussion Package: Clinical Care Language

Note: Because this is about clinical care language, it may be appropriate for agencies with clinical staff to invite them to this meeting.

In addition to the fact that clinical terms in health care are often complex and confusing to clients, many include a connotation of what is "good" and "bad" about client behavior as well as health status. Clients accessing HIV and OUD care who feel judged may experience health consequences and decide not to return to the care setting. Using non-judgmental and strengths-based language in discussing clients' behaviors and management of their conditions may facilitate communication with the client and retention in care.

Step 1: Review and confirm group agreements

Step 2: Choose one or more resources to view

Why Shouldn't Providers Judge Patients' Choices? | IHI Open School (2.5 minutes)
http://www.ihi.org/education/IHIOpenSchool/resources/Pages/AudioandVideo/Nia-Zalamea-Why-Shouldnt-Providers-Judge-Patients-Choices.aspx
Health care sometimes describes such patients as "noncompliant" or "difficult." In this video, Nia Zalamea explains why it's important for providers to avoid judging patients' health choices.

Stigma and OUD | Providers Clinical Support System (PCSS) (1.5 minutes)
https://www.youtube.com/watch?v=X-EzP2QcZcU
Nurse practitioner and PCSS expert Vanessa Loukas discusses stigma from the perspective of providers.

How does stigma complicate HIV/AIDS care? | UC San Francisco (UCSF) (3 minutes)
https://www.youtube.com/watch?v=wH9xo2Kingc
Nurse Diane Jones explains the psychological burden of the stigma associated with HIV, including how it affects accessing treatment.

Step 3: Discuss as a group

- What clinical terms might raise fear or sound judgmental and cause unintended harm to clients? Consider diagnostic terms; terms used to convey lab or screening test results, describe risk behaviors, and adherence to treatment recommendations; and any other situations in which clinical terms are used.
- What does the term "harm reduction" mean in your setting? Why is this definition important to your programs/services?
- Consider program policies. What words are used to describe expectations for service provision to clients? For example, in what ways can policies include language that supports clients' choices and health care needs (e.g., eligibility criteria, description of harm reduction services, and integration of harm reduction services with other clinical services)? How might program policies be written and communicated in ways that do not convey judgment or moralize client choices?
- Consider the language used when assessing client risk. Do policies and data collection requirements support neutral discussions about sexual histories and drug use? How can language maintain a neutral stance so that clients are comfortable sharing information and do not feel they need to gain approval?
- What clinical language might be exclusionary to people accessing services?
- What clinical terms related to HIV and/or OUD services in the system you work in could be modified to reflect more respect and dignity for clients' health conditions?

Step 4: Document action steps

Document the action steps suggested in response to the questions below in the staff meeting notes/minutes.

How can we make clinical language inclusive, respectful, and non-judgmental?

- What steps can we take to raise awareness of the importance of using non-judgmental clinical language in conversations with clients? Who needs to be involved in these steps?
- What steps can we take to review and improve the clinical language/terminology used in our written documents, including medical records, client communications, forms, signage, and policies? Who needs to be involved in these steps?

Step 5: Review additional resources

- Words Matter: Stigmatizing Language in Medical Records May Affect the Care a Patient Receives
  https://www.hopkinsmedicine.org/news/newsroom/news-releases/words-matter-stigmatizing-language-in-medical-records-may-affect-the-care-a-patient-receives

- Stop Talking 'Dirty': Clinicians, Language, and Quality of Care for the Leading Cause of Preventable Death in the United States
  https://www.amjmed.com/article/S0002-9343(14)00770-0/pdf

- Stigma in health facilities: why it matters and how we can change it
  https://bmcmedicine.biomedcentral.com/articles/10.1186/s12916-019-1256-2

- Respect to Connect: Undoing Stigma
  https://harmreduction.org/issues/harm-reduction-basics/undoing-stigma-facts/

- Words Matter - Terms to Use and Avoid When Talking About Addiction
  https://www.drugabuse.gov/nidamed-medical-health-professionals/health-professions-education/words-matter-terms-to-use-avoid-when-talking-about-addiction

Discussion Package: Referral Language

Care coordination for people with HIV and OUD requires being able to make appropriate and effective referrals within and across systems. The language that is used to describe services, members of care teams, and clients can affect client likelihood of following through with a referral.

Step 1: Review and confirm group agreements

Step 2: Read Client Scenario

Ask participants to read the case study below and/or ask someone to read it out loud to the group.

Pat is 38 years old, lives with a friend, and does not have a fixed address. At age 28, Pat was diagnosed with HIV and started antiretroviral treatment. Eight years ago, Pat was charged with possession and intent to sell heroin and was not offered a court diversion program. After more than a year of incarceration, Pat was released. Over the next four years he worked as a chef, starting and stopping buprenorphine treatment three times. During periods without work, Pat occasionally used unsterilized needles to inject fentanyl.

Pat began selling methamphetamine and fentanyl until he was re-incarcerated for three years, released, then re-incarcerated for lack of residence. Pat was released from incarceration last week and appears at your clinic seeking services. Pat has no established medical providers at this time.

Imagine you are a provider (e.g., physician, clinician, case manager) who has delivered HIV and/or SUD services to Pat and now needs to refer Pat for additional services.

Step 3: Discuss as a group

- How would you describe Pat (either verbally or in your notes)? Are there examples of person-first language you would use? (For more information see People First Respectful Language Modernization Act of 2006)
- Describe examples you know of in which use of terms about HIV and/or SUD has led clients to stop treatment and/or seek alternative providers.
- How might your choice of language to describe Pat to the referred provider affect the care Pat receives?
    - In what way can language help ensure a client's sense of safety with a new provider?
    - What language might be used to increase likelihood that an agency will be welcoming and respectful to the client?
    - What can you do to prepare clients for differences in language they might encounter while using the referred services?
- What terms would you use to describe the services to which you plan to refer Pat?
    - In what way might language that describes the referred services affect a client's willingness to engage with that care?
- What examples of terminology might increase likelihood of successful referrals?

Step 4: Document action steps

Document the action steps suggested in response to the questions below in the staff meeting notes/minutes.

How can we make sure that the language used for referrals is non-judgmental and welcoming?

- What steps can we take to raise awareness of the importance of the language used to describe clients and services while making referrals? Who needs to be involved in these steps?
- What steps can we take to review and improve the language or terminology used in our written documents, including medical records and referral forms, when making a referral? Who needs to be involved in these steps?

Step 5: Review additional resources

- A client-centered relational framework on barriers to the integration of HIV and substance use services; a systematic review
https://harmreductionjournal.biomedcentral.com/articles/10.1186/s12954-019-0347-x

- Why Language Matters: Facing HIV Stigma in Our Own Words
https://www.thewellproject.org/hiv-information/why-language-matters-facing-hiv-stigma-our-own-words

Discussion Package: Care Coordination Language

Care coordination and navigation ensure that individuals who have HIV and OUD receive the care they need within and between settings. As staff coordinate care, it is important that they use appropriate and accurate language to describe the client's health condition and health risks. Client-centered care includes using language and terms that are respectful, compassionate, and non-judgmental of clients' health status and risks.

Step 1: Review and confirm group agreements

Step 2: Read Client Scenario

Ask participants to read the case study below and/or ask someone to read it out loud to the group.

40-year-old Albert has diagnosed schizophrenia, HIV, and OUD. He receives disability income and lives alone in a small apartment. For five years, he saw an HIV case manager on a regular basis, but lately has missed a few appointments. He sees a psychiatrist at a community mental health center once a month to manage schizophrenia, and in the past two years has been receiving a buprenorphine prescription for OUD from the same center, which requires him to keep weekly appointments with a counselor. During his last visit, the counselor helped him to make a dental appointment. The counselor knows Albert has HIV but is unsure if he is getting HIV care. Albert's case manager is concerned and hopes to re-engage him in HIV care.

Scenario 1: The HIV case manager telephones the community mental health center to re-engage Albert in services and confirm his treatment status.

Scenario 2: The counselor at the community mental health center is concerned about Albert's HIV treatment status and wants him to have a dedicated case manager. The counselor telephones the HIV case manager.

Step 3: Discuss as a group

Choose one of the scenarios and describe how the client would be discussed in this conversation.

- What words might be used to describe Albert during this conversation?
- What words might be used to describe Albert's health status and risks?
- How might the language used to describe Albert and his needs affect the success of the care coordination?

Step 4: Document action steps

Document the action steps suggested in response to the questions below in the staff meeting notes/minutes.
How can we ensure that the language used in care coordination is inclusive, dignified, respectful, and non-judgmental?

- What steps can we take to improve the language used about client health conditions and risks when communicating across care systems? Who needs to be involved in these steps?
- What steps can we take to increase awareness of dignified, welcoming, and non-judgmental language to describe health conditions and risks across care systems?

Step 5: Review additional resources

- Linking to Care
  https://targethiv.org/library/topics/linking-care.

Discussion Package: Inclusive Client-centered Care Language

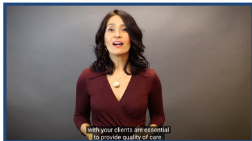
The language and norms of health care systems reflect the people who developed and operate them. The local context, culture, and people who most frequently use a particular system also shape it. This can result in care settings that are inclusive and accessible to some, but not all.

Information collected about client identities, experiences, and needs can contribute to holistic care provision. Many health systems administrators are acknowledging that racism and other forms of discrimination have a role in who receives care and the quality of that care.

Both the language used in the care system and the language used to describe clients are factors in effective and equitable care provision.

Step 1: Review and confirm group agreements

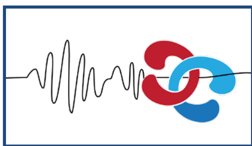
Step 2: Choose one or more resources to view



Practicing Cultural Humility: Developing Trust and Partnership With Clients |San Mateo County Health (4 minutes) https://www.youtube.com/watch?v=dpgQiN7qI-Y
Clients who trust their providers are more likely to be open with important information and engage in recommended treatment. This video offers health care providers suggestions for developing trust and partnership with their clients by practicing cultural humility.

Practicing Cultural Humility: Using Gender Pronouns |San Mateo County Health (3 minutes) https://www.youtube.com/watch?v=-ZfidMQjlbc
This video offers guidance for using gender pronouns respectfully and in line with clients' preferences as part of providing culturally humble care.

Developing, Understanding, and Strengthening Cultural Humility (7 minutes) https://globalsolidaritylocalaction.sites.haverford.edu/cultural-humility/ Video here: https://youtu.be/vEooo3vD3wE
This video describes the three core commitments of cultural humility: lifelong learning and critical self-reflection; recognizing and challenging power imbalances for successful partnerships; and institutional accountability.



Episode 5: Understanding Structural Racism within HIV and OUD Care |Strengthening Systems of Care for People with HIV and Opioid Use Disorder (31 minutes).
This episode of the Connecting Care podcast discusses the effects of structural racism at the intersection of HIV and OUD care and opportunities for providers and health care organizations to change.

Step 3: Discuss as a group

- Consider different aspects of individual identity including intersecting identities. In what way does cultural humility play a role in your care system?
- To what extent do the language and norms used in the care system reflect a particular culture or group of people?
- What are examples of language and norms used in the care system that some people may understand and others may not?
- Are client information forms structured in a way to capture a broad range of experiences, histories, and identities?
- How might the language used in the care setting affect clients who have experienced trauma (including trauma within the health care system)?

- How might language be used in consideration of historical mistrust of the care system?

Step 4: Document action steps

Document the action steps suggested in response to the questions below in the staff meeting notes/minutes.

How can we ensure that care is appropriate for and acceptable to all clients?

- What steps can we take to ensure language used at intake allows clients to express their identity? Who needs to be involved in these steps?
- What steps can we take to broaden the operationalization of cultural humility in our care system? Who needs to be involved in these steps?

Step 5: Review additional resources

- The Opioid Crisis and the Black/African American Population: An Urgent Issue
  https://store.samhsa.gov/product/The-Opioid-Crisis-and-the-Black-African-American-Population-An-Urgent-Issue/PEP20-05-02-001
- African-American women with HIV often overlooked, under-supported
  https://theconversation.com/african-american-women-with-hiv-often-overlooked-under-supported-109859
- Cultural Competency
  https://targethiv.org/library/topics/cultural-competency
- Behavioral health integration webinar series: Stigma
  https://www.ama-assn.org/practice-management/sustainability/behavioral-health-integration-webinar-series-stigma
- Breaking the Silence through Storytelling: Confronting Medical Mistrust to Advance HIV Prevention.
  https://getsfcba.org/resources/breaking-silence-storytelling/
- “Can I Trust You?” AIDS United’s Jesse Milan Jr. Delivers Keynote Address at 2020 AMSA Convention.
  https://www.aidsunited.org/blog/Default.aspx?id=3980 (39 minutes).
- “A ‘Rare Case Where Racial Biases’ Protected African-Americans: Fewer opioid prescriptions meant fewer deaths (possibly 14,000), but the episode also reveals how prevalent and harmful stereotypes can be, even if implicit.”
  New York Times, November 25, 2019.
  https://www.nytimes.com/2019/11/25/upshot/opioid-epidemic-blacks.html

APPENDIX

Glossary of Equity-Related Terms

Bias - Prejudice in favor of or against one thing, person, or group compared with another, usually in a way considered to be unfair.

Disaggregated Data - Typically, public institutions and systems report data on whole populations. However, greater access to and breakdown of racial data helps to underscore racial trends and disparities more clearly and will provide greater accountability .Creating visibility is the power of disaggregated data. There is a movement to go beyond the typically reported race categories to understand the variations that exist within these large groups.
For more: https://www.policylink.org/sites/default/files/Counting_a_Diverse_Nation_08_15_18.pdf

Cultural Appropriation - The adoption of elements of one culture by members of another culture. This can be controversial when members of a dominant culture appropriate from disadvantaged minority cultures.

Cultural Competence - The ability to respond appropriately to people of varying cultures, ages, races, religions, sexual orientations, abilities, and ethnicities in a way that recognizes difference and allows individuals to feel respected and valued. Cultural competence comprises four components: (a) Awareness of one's own cultural worldview, (b) Attitude towards cultural differences, (c) Knowledge of different cultural practices and worldviews, and (d) Cross-cultural skills. Developing cultural competence results in an ability to understand, communicate with, and effectively interact with people across cultures. Cultural competence is a developmental process that evolves over an extended period.

Cultural Humility - Originally described as a tool to educate physicians to work with the increasing cultural, racial and ethnic diversity in the United States, cultural humility is a lifelong process of self-reflection and self-critique whereby the individual not only learns about another's culture, but one starts with an examination of her/his own beliefs and cultural identities.This critical consciousness is more than just self-awareness, but requires one to step back to understand one's own assumptions, biases and values.

Culture - A way of life of a group of people -- the behaviors, beliefs, values and symbols that they accept, generally without thinking about them, and that are passed along by communication and imitation from one generation to the next.

Discrimination - A prejudice-based action taken by a dominant group member against a subordinate group member. These actions are used to limit another group's opportunities, confidence, access, and ability to perform in society.

Diversity - A fact, rather than a principle; diversity either exists or it does not. A diverse group, community, or organization is one in which a variety of social and cultural characteristics exist.

Equality - Evenly distributed access to resources and opportunity necessary for a safe and healthy life; uniform distribution of access that may or may not result in equitable outcomes.

Equity - The guarantee of fair treatment, access, opportunity, and advancement for all in every stage of employment, collaboration, and work at JSI, while at the same time striving to identify and eliminate barriers that have prevented the full participation of marginalized groups.

Implicit Bias - The attitudes or stereotypes that affect our understanding, actions, and decisions in an unconscious manner.

Inclusion - The act of creating environments in which any individual or group can feel welcomed, respected, supported, and valued.

Institutional Racism - Discriminatory treatment, unfair policies and practices, and inequitable opportunities and impacts based on race that occurs within institutions.

Interpersonal Racism - When private beliefs about race (e.g., bias, bigotry, or hate) are brought into interactions between individuals.

Internalized Racial Inferiority - The acceptance of and acting out of an inferior definition of self, given by the oppressor, is rooted in the historical designation of one's race. Over many generations, this process of disempowerment and disenfranchisement expresses itself in self-defeating behaviors.

Internalized Racial Superiority - The acceptance of and acting out of a superior definition is rooted in the historical designation of one's race. Over many generations, this process of empowerment and access expresses itself as unearned privileges, access to institutional power and invisible advantages based upon race.

Marginalization - Treatment of a person, group, or concept as insignificant or pervasive and places them outside of the mainstream society.

Microaggressions - Intentional or unintentional verbal,

nonverbal, or environmental slights / insults that communicate hostile, derogatory or negative messages to people based upon their marginalized group. There are 3 types: microassault, microinsult, microinvalidation

Microassault - Blatant verbal, nonverbal, or environmental attack intended to convey discriminatory and biased sentiments.

Microinsult - Unintentional behaviors or verbal comments that convey rudeness or insensitivity or demean a person's racial heritage/identity, religion, ability or sexual orientation identity.Microinvalidation - Verbal comments or behaviors that exclude, negate or dismiss the psychological thoughts, feelings or experiential reality of a target group. Are unintentional and usually outside of the perpetrator's awareness.

Power - Ability to control, coerce or influence people based on privilege identities. Power may be positional and provide access to social, political, and economic resources.

Privilege - Any unearned benefit, right or advantage one receives in society by nature of their identities.

Race - A social construct that artificially divides people into distinct groups based on characteristics such as physical appearance, ancestral heritage, cultural affiliation, cultural history, ethnic classification, and the political needs of a society at a given period of time.

Race Forward - A race forward approach recognizes that that the creation and perpetuation of racial inequities has been baked into government, and that racial inequities across all indicators for success are deep and pervasive. Focusing on racial equity provides the opportunity to introduce a framework, tools and resources that can also be applied to other areas of marginalization. Leading with race also recognizes that when looking within other dimensions of identity — income, gender, sexuality, education, ability, age, citizenship, and geography — there are inequities based on race. Knowing this helps organization take a more intersectional approach, while always naming the role that race plays in people's experiences and outcomes.

Racial Justice - The systematic fair treatment of people of all races that results in equitable opportunities and outcomes for everyone.

Respect - A feeling or understanding that someone or something is important, valued and should be treated in a dignified way.

Social Construct - An idea that appears to be natural and obvious to people who accept it but may or may not represent reality.

Social Justice - To take action as an advocate for a just society where all people have a right to fair and equitable treatment, support, and resources.

Structural Racism - The cumulative and compounded effects of an array of factors that systematically privilege white people and disadvantage people of color. Just as racism operates structurally and systemically, so too much racial equity in order to perpetually supplant racism