HIV and Stigma

OBJECTIVES

At the end of this unit, participants will be able to:

- Understand how language shapes our world
- Understand the history of language in relation to HIV and other chronic illnesses
- Define stigma and its impact on HIV prevention, treatment, and care
- Explain the differences between stigmatizing and empowering language
- Identify "People First Language" and its importance
- Explore the use of empowering language when talking or writing about oneself and others

INSTRUCTIONS

1. In preparation for the session, review slides and the notes.
2. Welcome participants.
3. Review the unit objectives.
4. Review slides 3–27 on HIV-related stigma, types of stigma, levels of stigma, impact, microaggressions, self-talk, history of HIV-related language, media, and People First Language, and engage participants in discussion throughout as prompted in slide notes.
5. Facilitate activity on stigmatizing self-talk vs. empowering self-talk (slide 28).
6. Facilitate optional activity on internal and external stigma.
7. Wrap up. Close by summarizing. Encourage participants to engage in self-care if the session has been triggering in any way.

Related C3 Roles

Providing coaching and social support; providing culturally appropriate health education and information; cultural mediation among individuals, communities, and health and social service systems

Related C3 Skills

Interpersonal and relationship-building skills, communication skills, education and facilitation skills

Method(s) of Instruction

Lecture, group discussion, group activity

Estimated time

60 minutes

Key Concepts

Stigma, internal stigma, external stigma, HIV language, stigmatizing macroaggressions, People First Language

Materials

- Computer with internet access and projector
- PowerPoint slides
- Paper and pens

Handouts

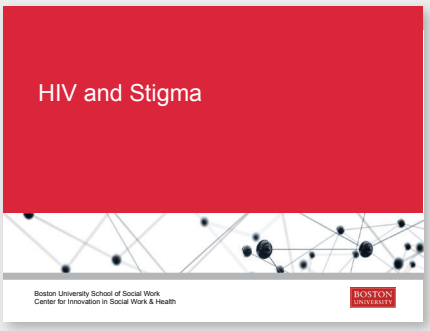
- Using Language that Empowers Worksheet
- Stigmatizing Language

Answer Key

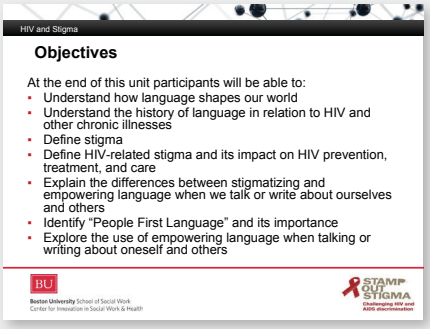
- Using Language that Empowers—Answers

Resources

Department of Health and Human Resources Health Resources & Services Administration's Ryan White Program available at: *https://hab.hrsa.gov/about-ryan-white-hivaids-program/about-ryan-white-hivaids-program*

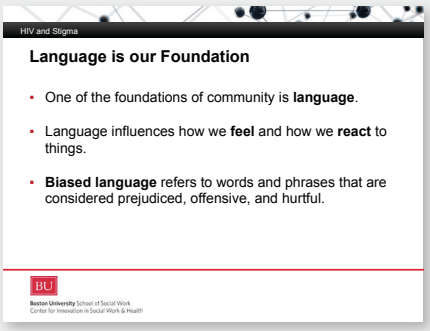


SLIDE 1



SLIDE 2

Review the objectives.



SLIDE 3

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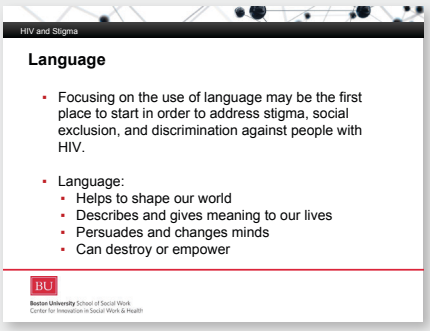
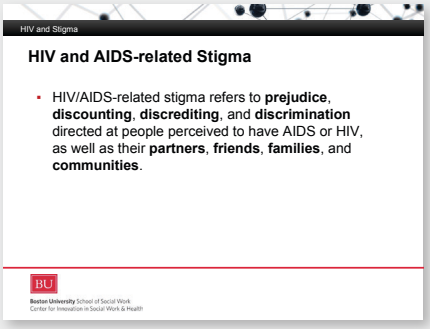


SLIDE 4

Review the slide.

SLIDE 5

Ask, "What is stigma? Can someone define stigma, not related to HIV? Who has experienced stigma? How?"



SLIDE 6

Review the slide and make the following points.

Stigma is borne out of fear and it represents one of the most complex and pervasive barriers to health care for people with HIV/AIDS.

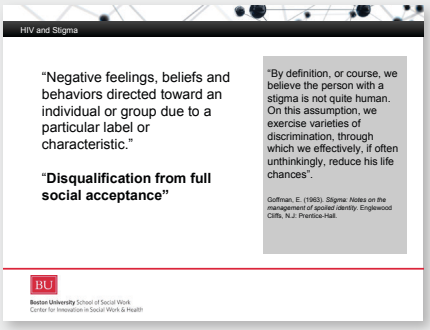
HIV/AIDS-related stigma often builds upon and reinforces other existing prejudices, such as those related to gender, sexuality, and race. For example, stigma associated with HIV is often based upon the association of HIV and AIDS with already marginalized and stigmatized behaviors, such as drug use and same-sex and transgender sexual practices.

Share the two major causes of stigma: Fear and ignorance.

People often do not know how HIV is or is not transmitted, so, fearing they might get infected through contact with a person with HIV, they isolate them.

Moral judgments: People know that HIV is transmitted mainly through sex or injecting drugs, so they assume that people with HIV get HIV through these activities. Therefore, they condemn people with HIV for "immoral" behavior. They don't consider people born with HIV.

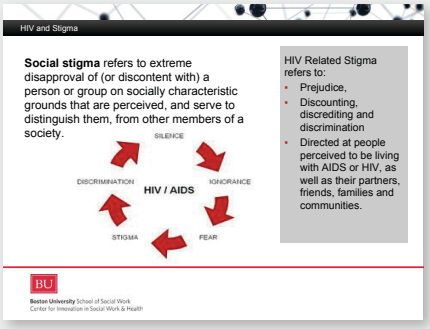
From the beginning, the Ryan White HIV/AIDS Program has fought against discrimination and the isolation that stigma creates. Ask participants how many people have heard of the Ryan White program? Explain that the Ryan White program is a federally funded program to help people with HIV to get care and treatment. The Ryan White Program made a commitment to help more people engage and remain in care.



SLIDE 7

Review the slide.

Stigma is a process where we (society) create a "spoiled identity" of an individual or a group of individuals. We identify a difference in a person or group, such as a physical difference (e.g., physical disfiguration), or a behavioral difference (e.g., people having lots of sex) and then mark that difference as a sign of disgrace. This allows us to stigmatize the person or group (i.e., they have already made up their mind about you).

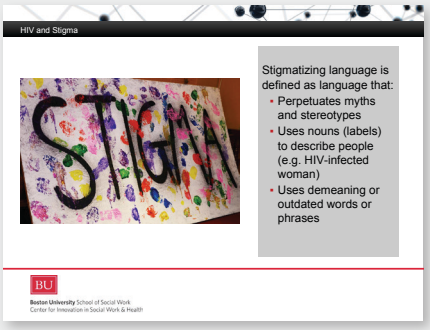


SLIDE 8

There are different types of stigma—social stigma is the exclusion of a person or group because of who and what they are perceived to be.

HIV/AIDS-related stigma refers to prejudice, discounting, discrediting, and discrimination directed at people perceived to have AIDS or HIV, as well as their partners, friends, families and communities. (Source: Herek, G. M. (1999). AIDS and stigma. *American behavioral scientist, 42*(7), 1106–1116.) So now it gets more expansive…it's not only people with HIV, but people that do the work to help them.

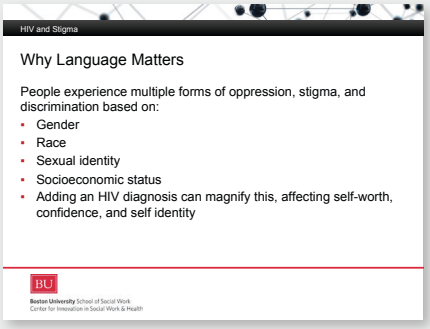
Ask if participants have any questions. HIV can be the elephant in the room in so many households, relationships, and organizations. It can be contentious, especially after a person shares their diagnosis with family or friends because of fear and lack of knowledge about HIV.



SLIDE 9

Review the slide.

Source: Patterson, J. B., and Witten, B. J. (1987). Disabling language and attitudes toward persons with disabilities. *Rehabilitation Psychology, 32*(4), 245.



SLIDE 10

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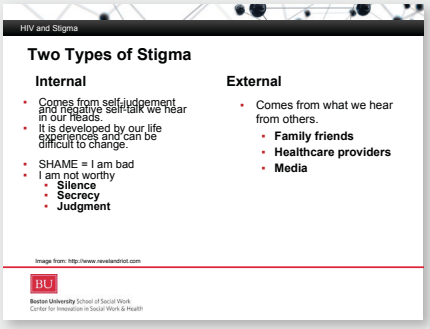


SLIDE 11

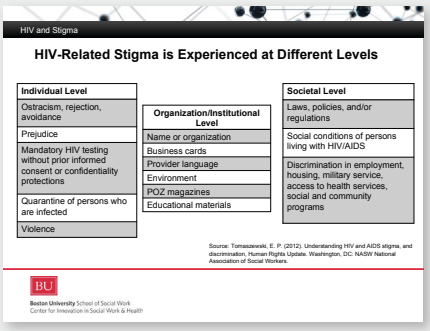
Review the slide.

There are two types of stigma, internal and external.

Internal comes from self-judgement while external comes from what we hear from others. The results from both types can include ignorance, discrimination, violence just to name a few.

Internal stigma can be difficult to change because it can be rooted in our life experiences. Some people who receive an HIV diagnosis have already experienced multiple forms of oppression and discrimination based on gender, race, or sexual identity.

External stigma can cause us to internalize the messages we get from others. For example, are you "clean" or "dirty" or "damaged"?



SLIDE 12

HIV and AIDS do not discriminate; people do. Let's briefly examine 3 different levels of stigma.

Individual level

A person may experience: Ostracism, rejection, avoidance, and prejudice.

Mandatory HIV testing of individuals without prior informed consent or confidentiality protections may occur.

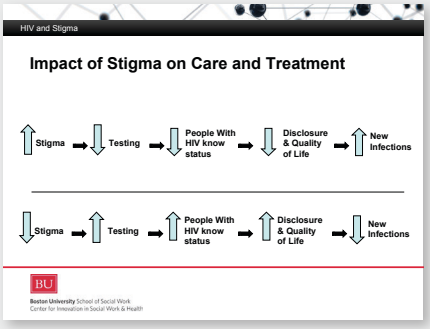
Violence can be a reality especially for the transgender community and other "high risk groups."

Organization/institutional level

Organizations also bear responsibility. If a clinic has the name "AIDS" or "HIV Clinic Services," people may choose to not visit it. If a CHW's business card says HIV/AIDS case manager, or the clinic's educational materials display sad photos, this may turn people away. Try to provide comfort in clinic rooms, making them warm and inviting.

Societal level

Stigma on a societal level seeks punishment by enacting laws and policies against people with HIV and AIDS, while other diseases are rarely mentioned. People with HIV face discrimination in employment, military service, housing, access to health services, and basic civil and human rights. For example, the criminalization of HIV transmission and forcible segregation of HIV positive prisoners. Organizations such as the Association of Nurse in AIDS Care (ANAC), the American Medical Association, the U.S. Conference of Mayors and many more support the modernization of state HIV-specific laws and prosecutions.



SLIDE 13

Review the slide.

Source: Herek, G. M. (1999). AIDS and stigma. *American behavioral scientist, 42*(7), 1106–1116.

When stigma is high, testing is low, fewer people know their status, fewer people disclose, and new infections rise. When stigma is low, testing increases, more people learn their status, more people disclose, and new infections drop. Unfortunately, people are sometimes stigmatized even in places they go for medical care and other services.

While access to appropriate treatment and care for individuals with HIV is generally recognized as a fundamental human right, discrimination can prevent people from getting tested and seeking or adhering to treatment and care due to the stigma associated with being HIV positive. For example in the United States, it is estimated that one in five persons with HIV is unaware of their HIV status. HIV stigma intensifies feelings of fear and isolation for people with HIV, which can compromise engagement in care.

Think about:

Counseling and Testing

A person is less likely to seek HIV testing in environments where they perceive workers to be judgmental about sexual activity and drug use. The use of less stigmatizing language is important in reducing stigma and empowering people with HIV and reflect the current science and the ways that people with HIV feel about themselves. Reducing stigma can help reduce HIV transmission by increasing disclosure and encouraging HIV testing.

Access to Care

People who exhibit concerns about stigma are more likely to delay care and/or not adhere to care.

Disclosure of Status

The decision to reveal one's HIV status is associated with a person's level of comfort. The more accepting, caring, and nonjudgmental a social network is toward HIV, the more likely the individual is to disclose.

Health Disparities

Consider stigma as it relates to racial/ethnic health disparities among communities of color when accessing HIV/AIDS services.

Isolates Families

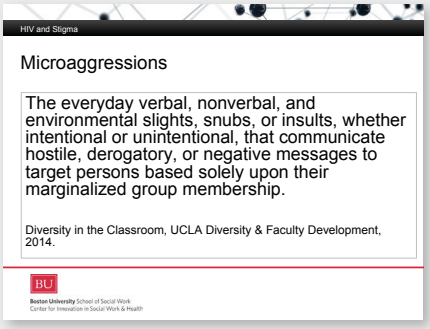
Stigma can discourage households from registering affected children in national support programs and further limits access to information, prevention, care, and treatment.

SLIDE 14

HIV infection is medically correct; however we don't have to refer to people with HIV as "infected".

When you think about someone being infected, what do you envision?

Instead, say "people with HIV."



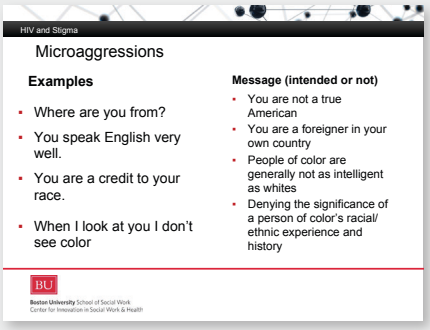
SLIDE 15

Review the slide.

Ask, "What microaggressions have you heard?"

Ask, "What is the connection between stigma and microaggressions?"

Encourage participants to discuss in dyads or small groups. Then elicit responses.



SLIDE 16

Review the slide for additional examples of microaggressions.

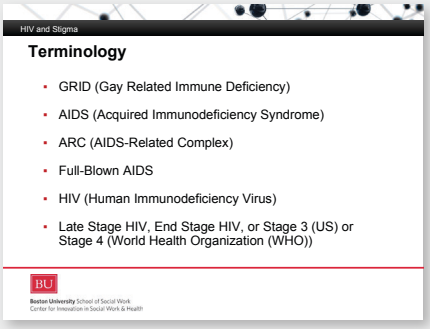
SLIDE 17

Review the slide for additional examples of microaggressions, and allow participants to respond.

Both stigma and microaggressions share similarities because they both stem from people's fears, ignorance, and judgments.

Microaggressions may be conscious or unconscious, and evoke shame in people. People are not aware of how stigma and microaggressions affect people with HIV. HIV stigma is wrong and unacceptable—it hurts people with HIV and affects their willingness to disclose and engage in care and other health enhancing practices.

SLIDE 18



SLIDE 19

HIV terminology and stigma

To understand the present, we must look at the past.

- GRID—Gay Related Immune Deficiency—was the original name for AIDS in 1982.
- AIDS—Acquired Immunodeficiency Deficiency Syndrome—changed from GRID to AIDS. GRID did not fully encompass the changing demographics of the disease. The first recognized cases were restricted to gay men.
- ARC—AIDS-related complex
- Full-blown AIDS
- HIV—Human Immunodeficiency Virus
- Late-stage HIV or end-stage HIV

All of these terms shaped how communities thought about this disease.

SLIDE 20

The media can have a big effect on changing the tide on stigmatizing language. However, the media has a lot of responsibility. Mainstream media reporting on HIV often sensationalize stories about people with HIV. Media coverage often includes disclosure of the person's identity, disclosing the person's HIV status not only to the individual's community but also, with the internet, to the world.

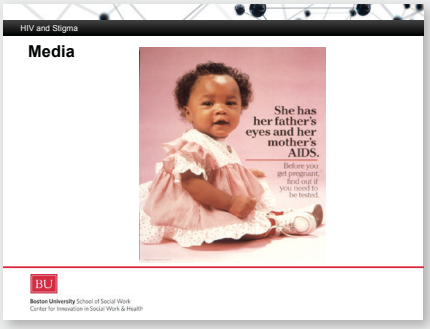
Media messaging can either support HIV prevention, care, and treatment efforts or hinder them.

Ultimately, the outcome of HIV messaging depends upon three things: The clarity of the message; the precision of the message; and the sensitivity of the message

Ask, "How did Time Magazine get this wrong?"

Take responses from participants.

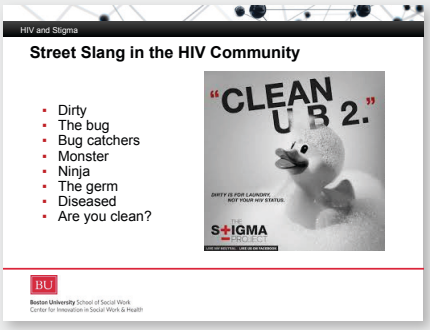
Answer: AIDS is not a virus, AIDS is a syndrome. AIDS, which stands for acquired immunodeficiency syndrome, is a condition characterized by progressive failure of the immune system.



SLIDE 21

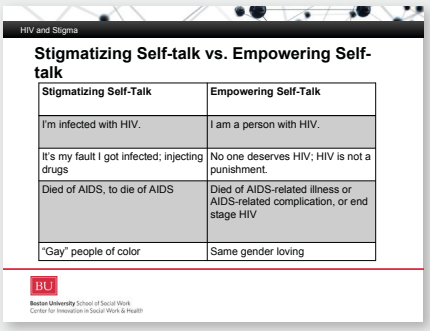
This poster is one of a series produced by Clement Communications, a public relations company that researches, creates, publishes, and distributes programs and materials to help organizations communicate with their intended audience. Designed to appeal to specific racial groups, each poster in the series features a different child. Although the child in the photograph appears to be happy and healthy, we learn from the message that her mother has given her AIDS. We see an emotional appeal to women—African-American women in this case—which along with the text suggests they have a responsibility beyond themselves to be tested for AIDS.

This ad shows a healthy baby but what is the message in the caption? Does the mother have a greater responsibility to be tested? What is the coded language from the media? Maybe the message is mothers with HIV should not have children?



SLIDE 22

These are examples of how language has been used in the HIV community in a negative way. How many of these have you heard?



SLIDE 23

Stigmatizing self-talk is "I'm infected with HIV." Empowering self-talk is "I am a person with HIV."

No one deserves HIV; HIV is not a punishment. HIV is a human disease that can affect anyone.

Incarcerated does not equal criminal. Being incarcerated does not define you as a person nor brand you as a criminal.

"Gay" people of color. Many people of color identify as same-gender loving rather than gay.

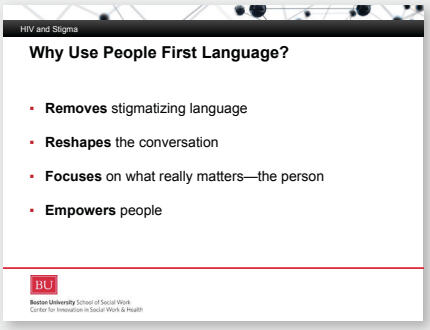
Transgender or gender-diverse people may use a pronoun that is different from what you might assume, so asking everyone what pronouns they use to show trans people they are welcome in your organization. Respecting people's core identify and the words they use to describe themselves is at the heart of putting people first.

SLIDE 24

Ask, "Who has heard the term "People First Language?"

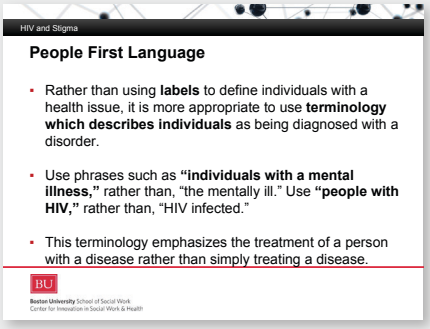
People First Language is an alternative way to talk about people with disabilities. It's putting people before the disability. To use People First Language, simply say the person's name or use a pronoun first, follow it with a verb, than state the name of the disability.

Using People First Language is not an attack nor does it call the disease to attention front and center. It puts the person first. We'll look at a few examples later.



SLIDE 25

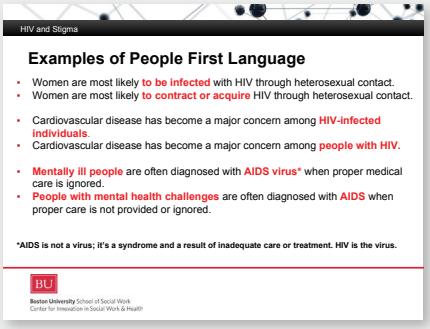
Review the slide.



SLIDE 26

Review the slide.

People First Language puts the person before the disability, illness or medical condition. A person is more than their medical diagnosis. People First Language helps to eliminate prejudice and it removes value judgements about the person. When we describe people by labels or medical diagnoses, we devalue and disrespect them as individuals.



SLIDE 27

We will look at a few examples that will help us distinguish between stigmatizing, incorrect, and insensitive language vs. what is preferred by communities.

Compare the first examples for each sentence (stigmatizing language) to the second example (People First Language).

SLIDE 28

Activity: Discuss stigmatizing language and its impact on people with HIV

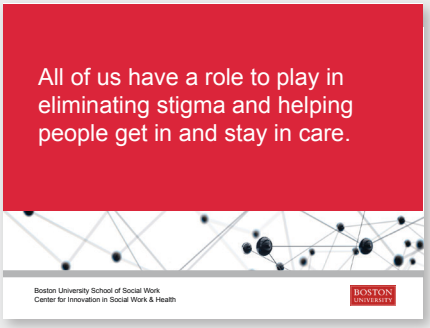
- Distribute Using Language that Empowers worksheet.
- Divide participants into small groups.
- Participants will brainstorm empowering statements that will convert or reframe stigmatizing language and microaggressions.
- Review responses as a large group.
- Ask, "What can you do to help reduce stigmatizing language?"

Discuss and make distinctions between external and internal stigma.

- External stigma (enacted stigma, discrimination) refers to the experience of unfair treatment by others.
- Internal stigma (felt stigma or self-stigmatization) refers to the shame and expectation of discrimination that prevents people from talking about their experiences and stops them from seeking help.

If any participants have disclosed that they are living with HIV, ask if they would be willing to briefly share their experiences by answering the following questions (3 minutes or less).

- What was a stigmatizing situation you have experienced since your diagnosis?
- How did it make you feel and what did you do?
- If the person has been living with HIV for several years (5 or more) would they feel any different if the situation were to occur today?



SLIDE 29

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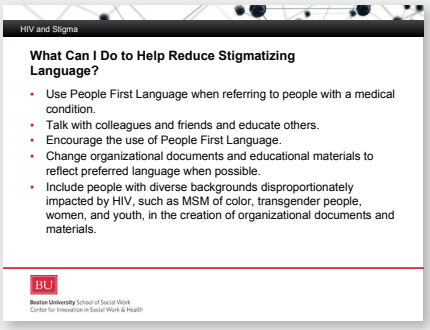

SLIDE 30

What can we all do to reduce stigma?

- Use People First language when referring to people with a medical condition.
- Talk with colleagues and friends and educate others. Encourage use of People First Language.
- Change organizational documents and educational materials to reflect preferred language when possible.
- Include people with diverse backgrounds disproportionately impacted by HIV, such as MSM of color, transgender people, women, and youth in the creation of organizational documents and materials. This will help ensure that language is culturally appropriate beyond the issue of HIV.

Optional activity

- In small groups, have participants develop situations that are examples of external stigma and internal stigma.
  - Example external stigma: A client has been expelled from their home due to their HIV status and sexuality.
  - Example internal Stigma: A client believes they deserved HIV because of their behaviors.
- Ask probing questions to help participants understand the impact stigma plays in providing services as a CHW.
- Example questions:
  - What impact can internalized stigma have on a person's motivation or willingness to work with a CHW?
  - In what ways can stigma impact a CHW's role effectiveness if they experience externalized or internalized stigma?

Emphasize that stigma separates and is counterproductive to building supportive, honest, and authentic working relationships with clients.

Summarize: Stigma can be a difficult topic because it often brings up hurt feelings, past aggressions, and negative experiences for people in general, not just people with HIV. Take some time for self-care if this lesson has triggered feelings for you.

Using Language That Empowers

Stigmatizing Statements and Microaggressions	Possible Interpretations/Implications	Empowering Statements
1. I'm infected with HIV.	I am a disease. I am nasty. I should be feared.	I am living with HIV. I have HIV. I have been diagnosed with HIV.
2. "That's so gay."		
3. I caught HIV by being "out there" bad.		
4. I got HIV from having risky sex.		
5. "You don't look like you have HIV at all!"		
6. We should target prostitutes for HIV testing day.		
7. He got HIV from "shooting up."		
8. "Anyone can be successful if they try hard enough."		

Using Language That Empowers—Answers

Stigmatizing Statements and Microaggressions	Possible Interpretations/Implications	Empowering Statements
1. I'm infected with HIV.	I am a disease. I am nasty. I should be feared.	I am living with HIV. I have HIV. I have been diagnosed with HIV.
2. "That's so gay."	Your culture is your most defining feature. Something is over the top, flamboyant, and exaggerated.	I am proud to be gay. That is so exaggerated or over the top.
3. I caught HIV by being "out there" bad.	HIV is easily spread through casual contact. I am bad or what I have done is bad; therefore, I deserve HIV.	I contracted HIV by [describe a behavior]. I am learning to live with HIV.
4. I got HIV from having risky sex.	What is risky sex?	I got HIV by having condomless sex, sex while using drugs, sex with more than one partner
5. "You don't look like you have HIV at all!"	People with HIV look sick.	People with HIV can look and feel healthy.
6. We should target prostitutes for HIV testing day.	Prostitutes do not use protection and are a greater risk than others. Labels objectify the person.	We could reach out to sex workers to offer testing.
7. He got HIV from "shooting up."	Injection drug use.	He contracted HIV by injecting drugs.
8. "Anyone can be successful if they try hard enough."	Implies laziness or inadequacies	Do your best. Give your best effort toward accomplishing your goals.

Stigmatizing Language

Stigmatizing	Preferred
AIDS virus	HIV
HIV/AIDS	HIV AIDS (only when referring to AIDS) HIV and AIDS
HIV virus	This is a redundant; use HIV
Promiscuous	This is a value judgment and should be avoided
Risk group	Risk
Risky sex – Unprotected sex	Sex without a condom
PLHA or PLWHA	People with HIV or Person with HIV
HIV patient, AIDS patient	Person with HIV
Positives or HIVers	People with HIV
AIDS/ HIV carrier	Person with HIV
AIDS victim or AIDS sufferer	Person with HIV
Died of AIDS, to die of AIDS	Died of AIDS-related illness or AIDS-related complications or end stage HIV
Victim	Person with HIV
Sufferer	Person with HIV
Contaminated	Do not use
Innocent (victim)	Do not use
AIDS orphans	Children orphaned by loss of parents or guardians who died of AIDS related complications
Full-blown AIDS	There is no medical definition for this phrase, simply use the term AIDS, or Stage 3 HIV
Zero new infections	Zero new transmissions/new cases
Mentally ill people	Person with a mental health challenges
HIV infected	Person with HIV
HIV infections	HIV transmissions, diagnosed with HIV
Number of infections	Number diagnosed with HIV/number of acquisitions
Compliant	Adherent
AIDS test	HIV test
To catch AIDS To contract AIDS To catch HIV	An AIDS diagnosis, developed AIDS, to contract HIV
Became infected	Contracted/acquired/diagnosed
HIV infected mother	Mother with HIV
Mother to child transmission	Vertical transmission, perinatal transmission
HIV infected baby	Baby with HIV
HIV exposed infant	Infant exposed to HIV
AIDS/HIV carrier	Person with HIV

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Team

Serena Rajabiun
Alicia Downes
LaTrischa Miles
Beth Poteet
Precious Jackson
Simone Phillips
Maurice Evans
Jodi Davich
Rosalia Guerrero
Maria Campos Rojo

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