Eliminating Stigma & Discrimination in Health Settings Delivering HIV Services



MODULE 2

INTEGRATING STIGMA ELIMINATION INTO DAILY CLINICAL PRACTICE













SECTION 1 STIGMA & DISCRIMINATION IN HEALTH FACILITIES



STIGMA IN HEALTH SETTINGS

- Combating HIV-related stigma is an important step towards:
 - Achieving public health goals
 - Controlling the HIV epidemic
 - Improving the general, mental & physical well-being of PLHIV
- Patient fear of stigma & discrimination are primary reasons why PLHIV are reluctant to be tested, disclose their HIV status, or start antiretroviral therapy





WHAT DOES STIGMA LOOK LIKE IN A FACILITY?

Some examples of stigmatizing practices & attitudes by facility staff:

- Neglecting or isolating HIV-positive people in areas of the facility
- Providing different or substandard care based on a patient's HIV status or whether she/he belongs to a key population (e.g., men who have sex with men, people who use drugs)
- Refusing to work with colleagues who are HIV positive
- Abusing a patient (verbally or physically) due to HIV status
- Gossiping is verbal abuse!







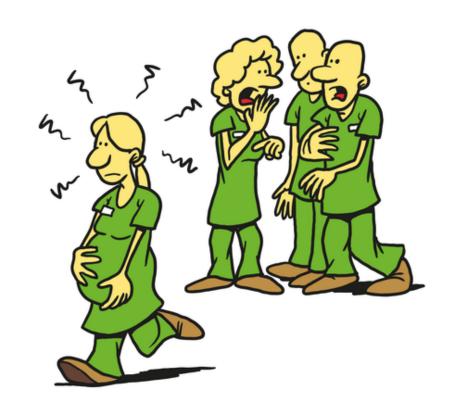
WHAT DOES STIGMA LOOK LIKE IN A FACILITY? (CONTINUED)

Stigma is a barrier to accessing & utilizing health services, leading to:

- Poor health outcomes
- Hampered efforts to end the HIV epidemic
- Achieving healthy lives for all

What does HIV stigma looks like in a health facility?

Sometimes health facility staff may adopt practices & attitudes that stigmatize patients & result in actions which are discriminatory







WHAT DOES STIGMA LOOK LIKE IN A FACILITY? (CONTINUED)

IAPAC Fast-Track Cities Quality of Life Survey:

 75% of people living with HIV who said they experienced stigma in a health facility indicated that it was at the hands of a health worker

Even one instance of health workers stigmatizing their patients is unacceptable.







WHAT DOES STIGMA LOOK LIKE IN A FACILITY? (CONTINUED)

Health care providers may:

- Perform poorly done, rushed examinations with minimal contact
- Unnecessarily use gloves & masks for routine tasks
- Delay or deny services
- Demand additional payment for services
- Violate patient privacy & confidentiality
- Use unfriendly verbal & body language
- Treat people with lack of respect, dignity





SECTION 2 STIGMA-FREE HEALTH FACILITIES





WHAT IS A STIGMA-FREE FACILITY?

A stigma-free health facility is one in which people living with HIV & other key populations are:

- Treated with respect & compassion
- Provided with high-quality care



Source: UNAIDS: Confronting discrimination: Overcoming HIV-related stigma and discrimination in healthcare settings and beyond. *UNAIDS 2017*





WHAT IS A STIGMA-FREE FACILITY?

All health care providers:

- Have a duty of care to patients
- Have a legal & moral obligation to adhere to the highest standards of quality care
- Should seek to ensure that patients are:
 - Given adequate information regarding their health condition & proposed treatments
 - Voluntarily consent to treatments & procedures
 - Are capable of understanding potential benefits & risks of their care

This duty is owed to all persons – without discrimination on any basis.



Source: UNAIDS: Confronting discrimination: Overcoming HIV-related stigma and discrimination in healthcare settings and beyond. *UNAIDS 2017*





STIGMA IN HEALTH SETTINGS (continued)

- Systematic review of HIV-related stigma in the United States
- Stigmatizing attitudes, beliefs, & behaviors remain barriers to:¹
 - Identifying HIV unawares
 - Linking patients to quality care
 - Increasing the numbers of people living with HIV who are virally suppressed
- Three themes were identified:²
 - Attitudes, beliefs & behaviors
 - Quality of care
 - Education & training

^{1.} Eaton LA, Driffin DD, Kegler C, et al. The role of stigma and medical mistrust in the routine healthcare engagement of black men who have sex with men. Am J Public Health 2015;105:75–82
2. HIV-Related Stigma by Healthcare Providers in the United States: A Systematic Review; Angelica Geter, Adrienne R. Herron, Madeline Y. Sutton AIDS Patient Care and STDs Vol. 32, No. 10 Behavioral and Psychosocial Research. Oct 2018



INTERNATIONAL ASSOCIATION OF PROVIDERS OF AIDS CARE

STIGMATIZING ATTITUDES, BELIEFS & BEHAVIORS

- Varied by gender, race, religion, provider category & clinical setting
- Most common among white, male, primary care physicians & providers with limited or no HIV stigma training in the past 12 months
- HIV-related stigma less likely among those who worked in settings where HIV-related anti-stigma policies were in place & reinforced
- Patients commonly stigmatized as:
 - Being poor or marginally poor
 - Having multiple sexual partners
 - Engaging in risky sexual behavior





QUALITY OF CARE

- Provider fear of acquiring HIV through occupational exposure led to:
 - Reduced quality of care
 - Refusal of care
 - Anxiety when providing services to PLHIV
- Higher among providers with limited awareness or access to postexposure prophylaxis (PEP) within their clinic
- Patient–provider discordance
 - Importance of addressing HIV-related stigma
 - Reduced quality of care or patient satisfaction



EDUCATION & TRAINING

 Non-HIV-specialized physicians who have limited opportunities for clinical education & practice are more likely to stigmatize their patients

- Lower rates of stigmatizing attitudes reported among:
 - Healthcare providers who received HIV stigma training in the past 12 months





IS YOUR FACILITY FREE FROM STIGMA?

These are the minimum standards set by UNAIDS:

- Timely & quality health care is provided to all people in need
- Informed consent is secured before any tests are carried out
- People are not forced to submit to or pay for services
- People's privacy & confidentiality respected
- Health providers are trained to deliver services free from stigma
- Mechanisms are in place to redress episodes of enacted stigma (discrimination)
- Affected communities meaningfully participating in the development & monitoring of policies & programs is encouraged







IS YOUR FACILITY FREE FROM STIGMA? (continued)

One year after the *Agenda for Zero Discrimination in Health Care was* launched, UNAIDS reported examples of countries moving to discrimination-free health care for all

In Argentina, 21 health facilities committed to increase accessibility & acceptability for lesbian, gay, bisexual, & transgender (LGBT) people:

- Training of health care providers on LGBT health needs
- Accessible opening hours
- Active involvement of LGBT people in the design & functioning of services provided at facilities







MAKING YOUR HEALTH FACILITY STIGMA FREE

Make your health facility stigma free through the following practices:



- Adopt a code of conduct to end stigma in your facility
- Ensure that PLHIV & other key populations receive the same standard of care as other patients
- Provide a friendly & welcoming environment for your patients
- Speak up & challenge health workers who stigmatize patients
- Support health workers at your facility to be tested for HIV, providing full backing of staff & management if diagnosed HIV positive







CASE STUDY

- Henry is a 33-year-old man with a long history of homelessness, incarceration & limited social support.
- He has been in & out of jail for many years.
- He has struggled with alcohol & substance use.
- He was diagnosed with HIV in 2010. He never accepted the diagnosis, felt that his life was finished & started to drink & use drugs.
- He has grappled with adherence to his antiretrovirals in the past, often going without medication for months when he was living on the street.







CASE STUDY (continued)

- During his most recent 18-month incarceration for theft, he has taken his HIV medication regularly & his viral load has been undetectable.
- But on release from prison, he immediately sought out his old friends & began drinking heavily again.
- Despite having an HIV care continuum case manager, Henry quickly loses contact with her & stops going to the HIV clinic because he heard staff members saying that he was a "smelly, homeless drunk."
- Two months after his release, Henry is arrested again for shop-lifting.

Eliminating Stigma & Discrimination in Health Settings Delivering HIV Services





As health workers, we can & must take responsibility for reducing discrimination in our facilities

Talk about discrimination whenever the opportunity arises



Do not discriminate

Especially the most vulnerable

Challenge others if they discriminate

Develop & implement facility-wide policies to eliminate stigma & discrimination

HENRY'S CASE





CASE STUDY



- Gabrielle is a 30-year-old African-American woman living with HIV.
- Her husband is HIV negative & they have been married for 4 years.
- Gabrielle has been on antiretrovirals since her HIV diagnosis 7 years ago. She never misses her antiretroviral doses & has had an undetectable viral load for many years.
- The couple has no children but Gabrielle has been thinking that she would like to have a baby before she gets much older.
- She wanted to chat with her primary care physician but was unsure about what reaction she would get. Her physician never talks about Gabrielle's reproductive choices.





CASE STUDY



- She knew her physician was quite conservative & Gabrielle was his only HIV-positive patient. Finally, she asked the doctor about getting pregnant.
- As Gabrielle predicted, her physician advised her that getting pregnant was not a good idea. He said that a pregnancy could upset her viral suppression & that the baby might be born "with problems."
- Gabrielle decided to get another opinion from an HIV specialist.
- Following the HIV specialist's advice that many HIV-positive women now are having children, she & her husband decided to have a baby.
- Her baby is now 12 months old. Both Gabrielle & her infant (Tom) are healthy.
- Gabrielle is planning her second pregnancy.

Eliminating Stigma & Discrimination in Health Settings Delivering HIV Services





A legacy of stigma persists despite medical advances that make childbearing among people living with HIV much safer¹



Reproductive intentions of people living with HIV have been largely neglected with consequences for public health & human rights¹



Provider-initiated conversations with people living with HIV about reproductive plans are often lacking²



I can't believe that is really a question... The bottom line is everyone deserves to have kids. Yes, I have HIV. No, I did not want [HIV], but I still want a family, I still want a life... everyone deserves that right.³

GABRIELLE'S CASE



SECTION 3 WHAT CAN YOU DO TO ELIMINATE STIGMA?





CHECKLIST FOR EVALUATING STIGMA

Provide patients a checklist to self-evaluate stigma:

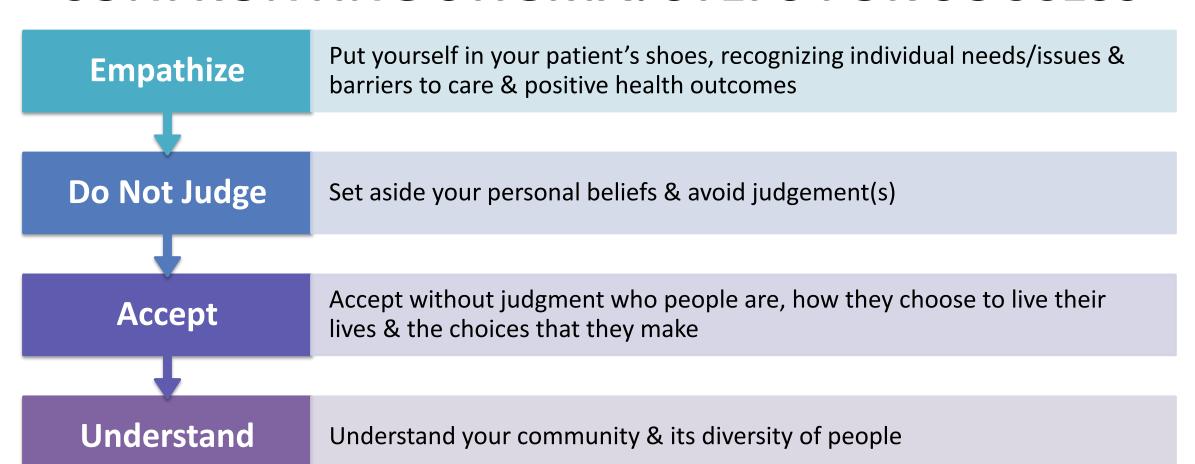
- Are you currently experiencing stigma in your community?
 - If so, how does it affect your daily life?
- Are you currently experiencing stigma at this health facility?
 - If so, who at this health facility stigmatizes you? How?
- Is stigma affecting the care that you receive at this health facility?
- Do family members or friends know about your HIV status?
- Do you feel ashamed because of your HIV status?
- Did you feel that others blame you for your HIV status?
- Do you have access to a support network?







CONFRONTING STIGMA: STEPS FOR SUCCESS

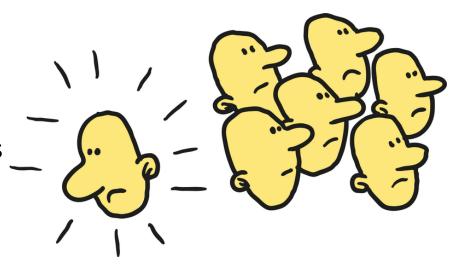






UNDERSTANDING INTERSECTIONAL STIGMA

- Stigma affects different groups of people in different ways, based on age, gender, race, ethnicity, sexual orientation, gender identity, religion & socioeconomic status
- People living with HIV are marginalized because of social identities & inequities
- Overlapping stigma forms basis for intersectional stigma:
 - Women can face dual stigma gender & their HIV status
 - Men who have sex with men who are living with HIV can be dually stigmatized for their sexuality & HIV status
 - Men & women living with HIV who belong to a minority race or ethnicity can experience multilevel stigma
 - Stigma may be more severe among older people



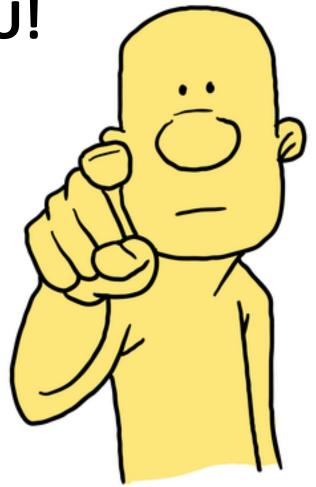




IT STARTS WITH YOU!

Taking Steps towards De-Stigmatization

- Every staff member in your healthcare facility including you – has a responsibility to make all people feel welcome & to treat them with the respect & dignity to which they are entitled
- Failing to provide a welcoming, convenient & safe environment contributes to disengagement in care, loss to follow-up & poor health outcomes







IT STARTS WITH YOU! (CONTINUED)

Recognize

- Recognize that stigma & discrimination exists in your health facility
- Recognize that staff need to be empowered to speak out & report stigmatizing practices when they occur without fear of reprisal

Address

- Address misconceptions about HIV transmission
- Staff fear of acquiring HIV through casual contact is a major reason for stigmatizing & discriminating practices in health facilities

Reduce

- Reduce the distance between patients & staff
- Staff need to have empathy for their patients



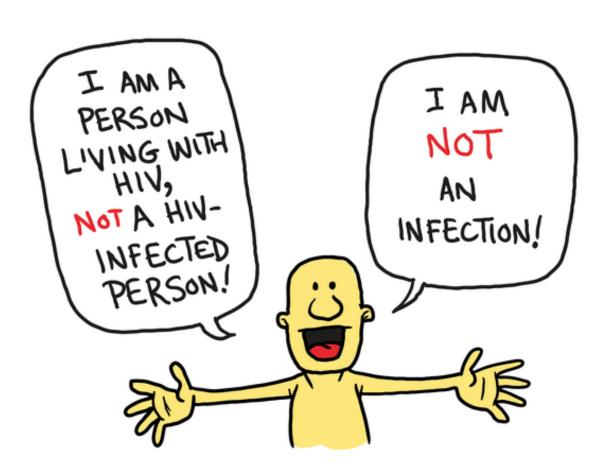


FOSTERING STIGMA-FREE COMMUNICATION





LANGUAGE MATTERS! FOSTERING STIGMA-FREE DIALOGUE



- Your language will either empower your patients or keep them from accessing & utilizing HIV care & other services
- Use "Person First" language
 - Person-first language puts the person before their health condition (i.e., HIV positive status)
 - Make sure you are not referring to your patients as "HIV positives" or "HIV-infected persons" but rather as "people living with HIV"





LANGUAGE MATTERS! (CONTINUED)



- Effective health provider-patient communication is a critical component to ensuring that patients receive the care & support they need
- HIV treatment adherence is specifically affected by ineffective communication





LANGUAGE MATTERS! (CONTINUED)

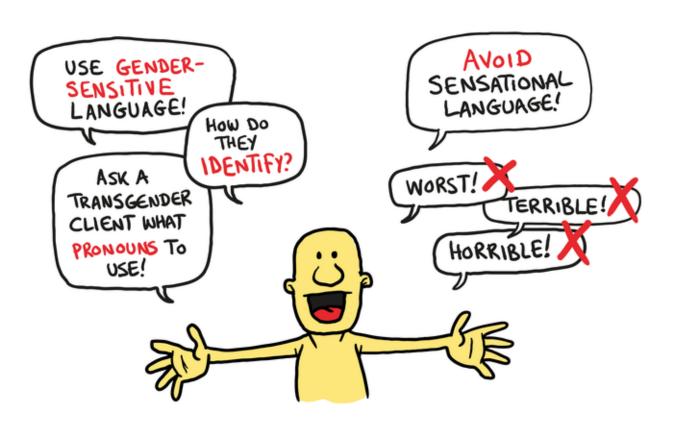


- IAPAC's Caliber of Care Program is a resource for health workers to optimize their communication with people living with HIV seeking care in a health facility
 - The Caliber of Care Stigma Dialogue Navigator provides guidance for stigma-free communication
 - You may access the resource at www.iapac.org





LANGUAGE MATTERS! (CONTINUED)

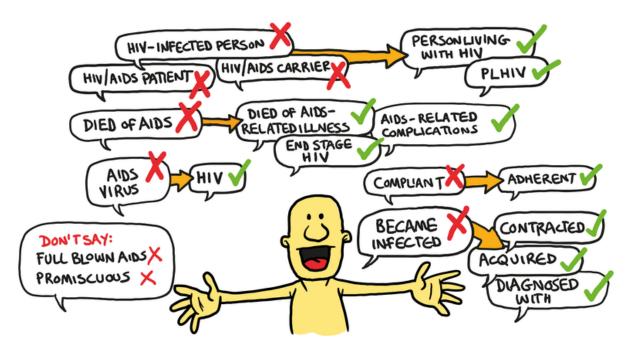


- Ask your patients how they identify & what they wish to be called
- Use gender-sensitive language
- Avoid using sensational language





SAY THIS, NOT THAT!



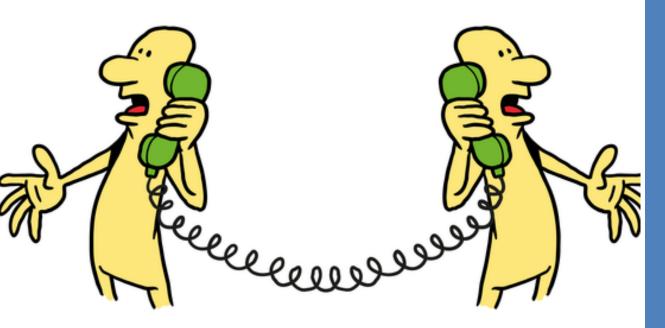
Stigmatizing language	Preferred language
HIV-infected person, AIDS patient, or HIV carrier	Person living with HIV
Died of AIDS	Died of an AIDS-related illness
AIDS virus	HIV (AIDS is a diagnosis, not a virus)
Full-blown AIDS	No medical definition for this term; simply use the term AIDS
Became infected with HIV	Acquired HIV
Compliance, compliant	Adherence, adherent
Promiscuous	Value judgment to be avoided; use "multiple partners"

Source: IAPAC Caliber of Care Stigma Dialogue Navigator





TWO-WAY LINE OF COMMUNICATION



"You have to be honest with your care provider. If you didn't take the medicine or you had unprotected sex, you got to tell all of that."

Healthcare providers must be honest with patients, too; if the viral load is high, the patient needs to know that so that joint action can be taken.

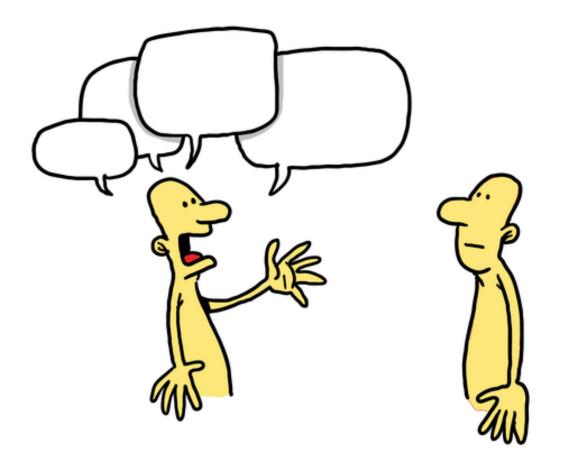
Source: IAPAC Caliber of Care Stigma Dialogue Navigator





CONVERSATION STARTERS

- "I know experiencing stigma & discrimination can be at times very painful."
- "You are in a safe & confidential space here. It's okay to share."
- "If you feel stigmatized in this facility, say something. Speak up."
- "Sharing what you're going through with others you trust can be an important part of dealing with your HIV."



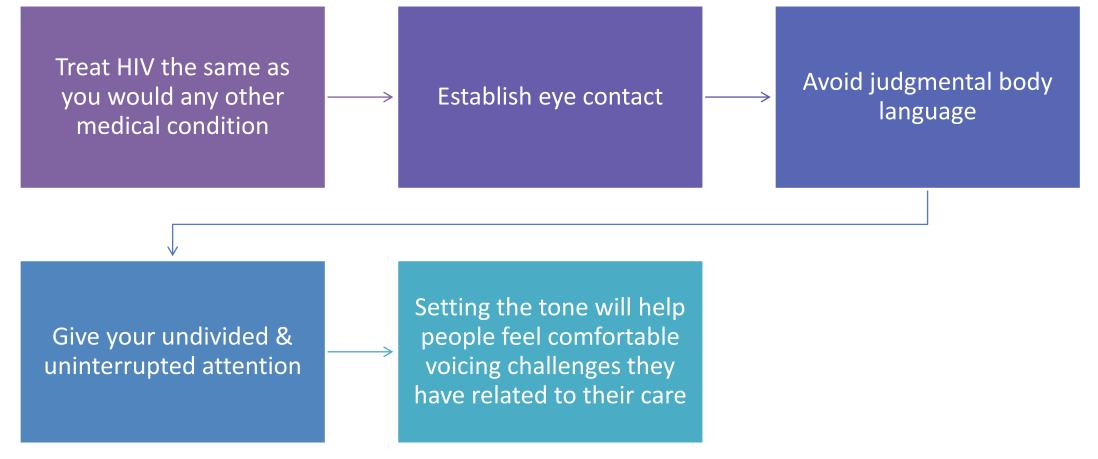


SECTION 5 OTHER STRATEGIES TO ELIMINATE STIGMA





TREAT BY EXAMPLE



Source: IAPAC Caliber of Care Stigma Dialogue Navigator





TREAT BY EXAMPLE (CONTINUED)

1

Provide a welcoming & nurturing environment

 Encourage your patients to talk openly about their experiences & needs 2

Ask questions about perspectives on HIV & approaches to care

 "What goals do you have for our appointment today?" 3

Remind people that all discussions with you & other staff are & will remain confidential





KEEP A PULSE ON YOUR COMMUNITY

1

Keep a pulse on the community where you practice



Understand the terms people are using when discussing HIV in order to better relate to them



Be aware of local events & activities that could be supportive platforms for combating HIV stigma





EMPOWER PLHIV TO OVERCOME STIGMA

Knowledge is power

- A treatment-literate person:
 - Is better equipped to make informed decisions
 - Can more effectively face stigma & discrimination
- Encourage the use of peer educators who can partner with new patients & guide them with strategies for responding to stigma
- Provide mentoring skills training to your staff, who should:
 - Avoid lecturing or passing judgment
 - Provide constructive guidance





MORE STEPS FOR SUCCESS

To facilitate a stigma-free environment:

Provide comprehensive HIV information & education in an easily understood manner

Offer regular opportunities to share information on HIV treatment with your clients & answer their questions

Link people living with HIV to services that support their holistic well-being

Provide support for HIV status disclosure





U=U (B=B, I=I, K=K, N=N)

- PLHIV who achieve undetectable viral load cannot transmit HIV (Undetectable = Untransmittable)
 - Evidence-based message
 - HPTN 052, PARTNER, PARTNER 2, Opposites Attract
 - De-stigmatizes an HIV diagnosis & living with HIV
- Talk to your patients about how U=U works:
 - Importance of treatment adherence to remain healthy & prevent transmission to serodiscordant partners
 - Necessity of staying undetectable for U=U to work
- Encourage your patients to know their viral load so that they are aware of their undetectable status

UNDETECTABLE = UNTRANSMITTABLE



B=B (Turkish); I=I (Italian, Portuguese, Spanish); K=K (Vietnamese); N=N (Dutch)







FOSTERING HUMAN RIGHTS

Tell	Display	Communicate	Provide	Train
Tell people about their rights	Display these rights in written form & place them on prominent display in your clinic	Specifically communicate these resources to people regularly	Provide information about local organizations that can provide counseling & legal services	Train your employees on human rights & their role, as health care workers, in empowering people to be engaged meaningfully in their care



SECTION 6 SUMMARY

Eliminating Stigma & Discrimination in Health Settings Delivering HIV Services





Adopt a code of conduct to end stigma in your facility



Train & retrain staff about stigma to reinforce knowledge



Educate your staff & patients about HIV, including U=U



Create & maintain a welcoming environment for all patients



Use non-stigmatizing language to avoid communication barriers



Ensure that all people receive same standard of care

SUMMARY OF KEY STRATEGIES TO ELIMINATE STIGMA





REFLECTION POINTS

- Let's reflect upon the content from Module 2:
 - What does stigma look like within a health facility?
 - What constitutes a stigma-free health facility?
 - Is your facility free from stigma? If not, how can you make it so?
 - How can you evaluate stigma experienced by your patients?
 - In what ways can you improve communication & dialogue with your patients?
 - How can you assist patients to overcome stigma?
 - What is U=U? How can you integrate this message into clinical practice?
 - How can you realize the human right of your patients to stigma-free health services?





VIDEO RESOURCES

- Two videos from SisterLove (USA):
 - Stigma & Disclosure
 - Talking to Your Provider
- Everyone Has a Story: Conversations of Survival and Leadership
- Videos from the <u>Martin Fisher Foundation</u> (UK):
 - Making HIV History (an animated cartoon dispelling myths about HIV)
 - We Learn, We Think, We Change
 - Kissing Testing & Hugging are Okay
 - Meet Some People with HIV
- Stigma & Discrimination in HIV (India):
 - 22 videos covering stigma & discrimination in health care
 - Health Policy Plus supported by the US National Institute of Mental Health





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