# STIGMA IN HEALTH SETTINGS

- Combating HIV-related stigma is an important step toward:
  - Achieving public health goals
  - Overcoming the HIV epidemic
  - Improving the general mental and physical well-being of people living with HIV
- Patient fear of stigma and discrimination are primary reasons why people living with HIV are reluctant to be tested, disclose their HIV status, or start HIV treatment

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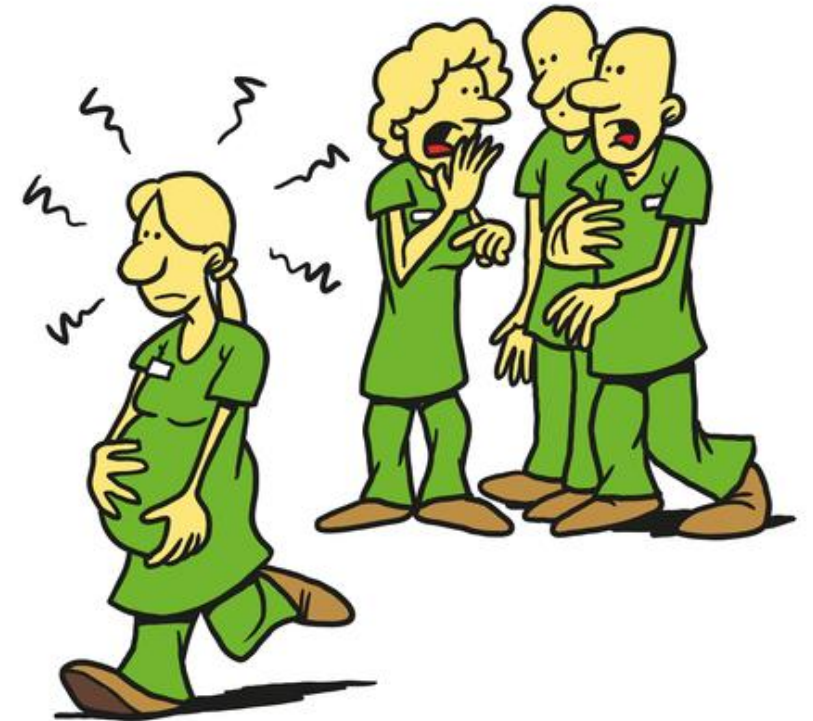
WHAT DOES STIGMA LOOK LIKE IN A FACILITY?
(CONTINUED)

- **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

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*

STIGMA IN HEALTH SETTINGS

- Systematic review of HIV-related stigma in the United States (Oct 2018)
- Stigmatizing attitudes, beliefs, and behaviors remain barriers to [1]…
  - Identifying HIV unawares
  - Linking patients to quality care
  - Increasing the numbers of PLHIV who are virally suppressed
- 3 themes identified [2]
  - Attitudes, beliefs, and behaviors
  - Quality of care
  - Education and 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

STIGMATIZING ATTITUDES, BELIEFS, AND BEHAVIORS

- Varied by gender, race, religion, provider category and clinical setting
- Most common among white, male, primary care physicians and 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 and reinforced
- Patients commonly stigmatized as
  - Being poor
  - Having a large number of sexual partners
  - Engaging in risky sexual behavior

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

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 post-exposure prophylaxis within their clinic
- Patient–provider discordance
  - Importance of addressing HIV-related stigma
 - Reduced quality of care or patient satisfaction

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

EDUCATION AND TRAINING

- Non-HIV specialty doctors who have limited opportunities for clinical education and practice are more likely to stigmatize

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

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

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
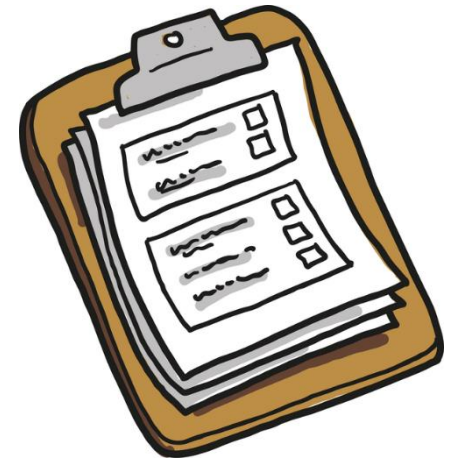
MAKING YOUR HEALTH FACILITY STIGMA FREE

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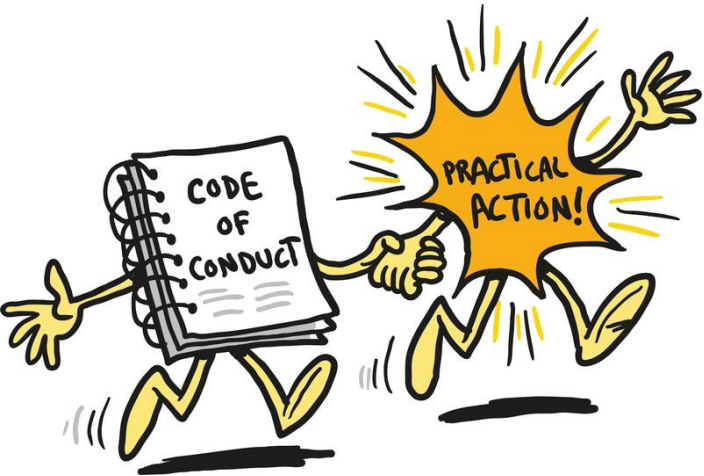
- Adopt a code of conduct & action plan to end stigma in your facility
- Ensure that PLHIV & other key populations receive the same standard of care as other patients
- Provide a friendly & welcoming environment for your patients
- Speak up about & challenge health workers who stigmatize patients
- Support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

The following case study of Henry is an example of multiple factors, including stigma, resulting in interruption of care at a particularly vulnerable time in his life

CASE STUDY

- Henry is a 33 year old man with a long history of homelessness, incarceration and limited social support.

- He has been in and out of jail for many years and has struggled with alcohol and substance abuse.

- He was diagnosed with HIV in 2010. He never accepted the diagnosis, felt that his life was finished and started to drink and 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.

- During his most recent incarceration for 18 months for theft, he has taken his HIV medication regularly and his viral load has been undetectable. But on release from prison, he immediately seeks out his old friends and begins drinking heavily.

- Despite having a care continuum case manager, Henry quickly loses contact with him and 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

FAST-TRACK CITIES | IAPAC
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As health workers, we can & must take responsibility for reducing discrimination in our facilities

Talk about discrimination whenever the opportunity arises

Change our personal attitudes & behavior

| Don't discriminate | Especially the most vulnerable |

Challenge others if they discriminate

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

LEARNING FROM HENRY'S CASE

References: Dolan K Saber-Tehrani AS, Stephenson BL, MacGowan RJ, Tsang J Binswanger IA

CHECKLIST FOR EVALUATING STIGMA

Provide patients a checklist to self-evaluate stigma in a health facility:

- 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? And, how?
- 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 or different from others because of your HIV status?
- Did you feel that others blame you for your HIV status?
- Do you have access to a support network?

The following case study of Gabrielle is an example of how stigma jeopardizes access to quality HIV care.

CASE STUDY

- Gabrielle is a 30 year old African-American woman living with HIV.
- Her husband is HIV negative and they have been married for 4 years. Gabrielle has been on antiretroviral therapy since her HIV diagnosis 7 years ago. She never misses her ARVs and 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 doctor but was unsure about what reaction she would get. Her doctor never talks about Gabrielle's reproductive choices.
- She knew her doctor was quite conservative and Gabrielle was her only HIV positive patient. Finally, she asked the doctor about getting pregnant.
- As Gabrielle predicted, the doctor advised that this was not a good idea as it could upset her viral control and the baby may have problems.
- Gabrielle decided to get another opinion from a HIV specialist and, following advice that many HIV positive women now are having children, she and her husband decided to have a baby.
- Her baby is now 12 months old and both she and her infant are healthy.
- Gabrielle is planning her second pregnancy.

A legacy of stigma persists despite medical advances that make childbearing among people living with HIV much safer [1]

Reproductive intentions of people living with HIV have been largely neglected with consequences for public health and human rights [1]
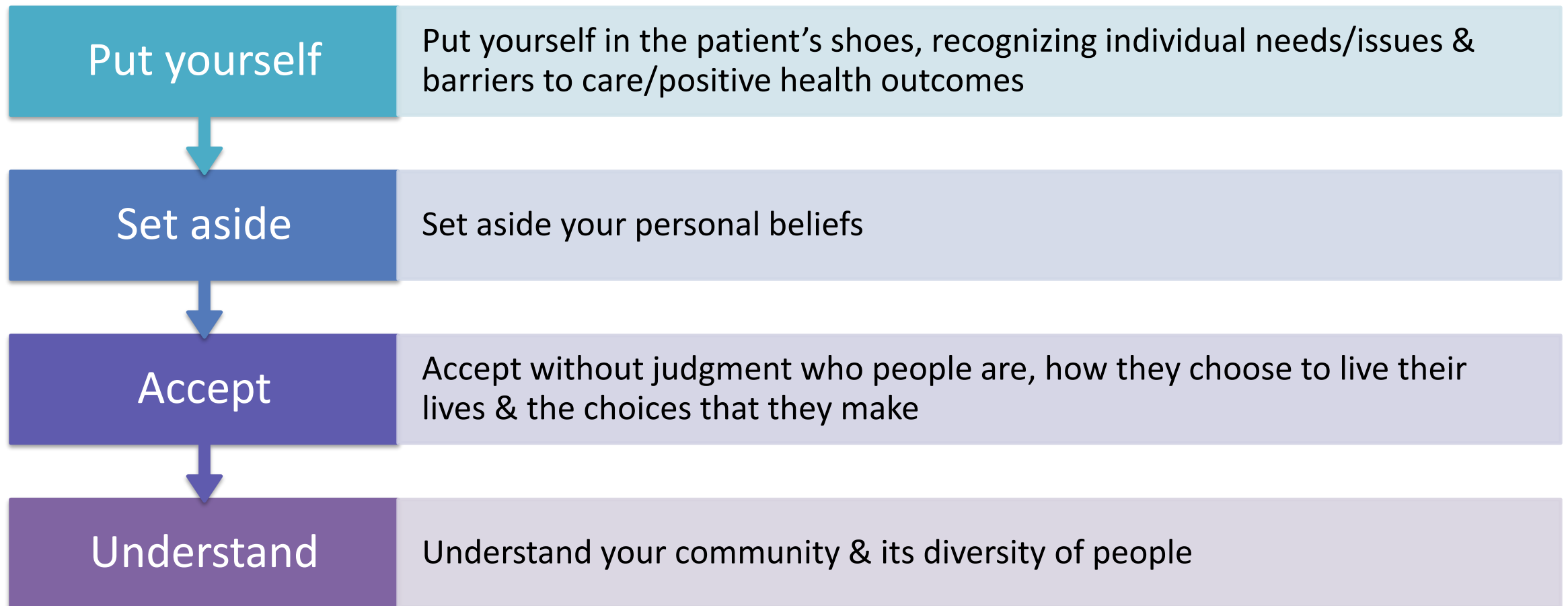
Provider-initiated conversations with people living with HIV about reproductive plans are often lacking [2]

I can't believe that is really a question . . . . The bottom line is everyone deserves to have kids. Yes, I have HIV. No, I didn't want [HIV], but I still want a family, I still want a life ... everyone deserves that right. (24-year-old female) [3]

LEARNING FROM GABRIELLE'S CASE

References: 1. Steiner RJ 2. Mindry D. 3. Finocchario-Kessler S

CONFRONTING STIGMA: STEPS FOR SUCCESS

| Put yourself	Put yourself in the patient's shoes, recognizing individual needs/issues & barriers to care/positive health outcomes
Set aside	Set aside your personal beliefs
Accept	Accept without judgment who people are, how they choose to live their lives & the choices that they make
Understand	Understand your community & its diversity of people

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, multilevel forms of stigma form the basis for intersectional stigma:
  - Women can face dual stigma for both their gender as well as their HIV status
  - Men who have sex with men who are living with HIV can be dually stigmatized for both their sexuality & HIV status
  - Men & women living with HIV belonging to a minority race or ethnicity within their community can experience multilevel forms of stigma
  - HIV-related stigma may be more severe among older people
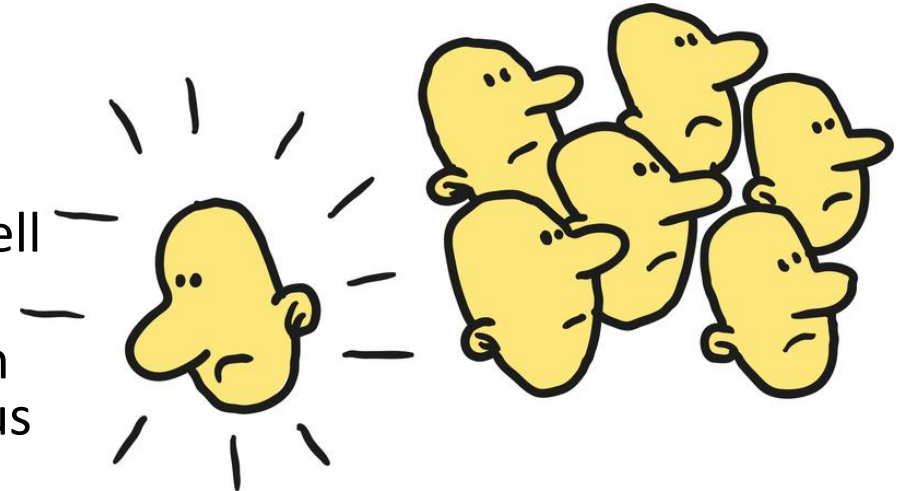
IT STARTS WITH YOU!

Taking Steps Towards De-Stigmatization

- Every staff member in your healthcare facility – including you – has a responsibility to make all people feel welcome and to treat them with the respect and 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
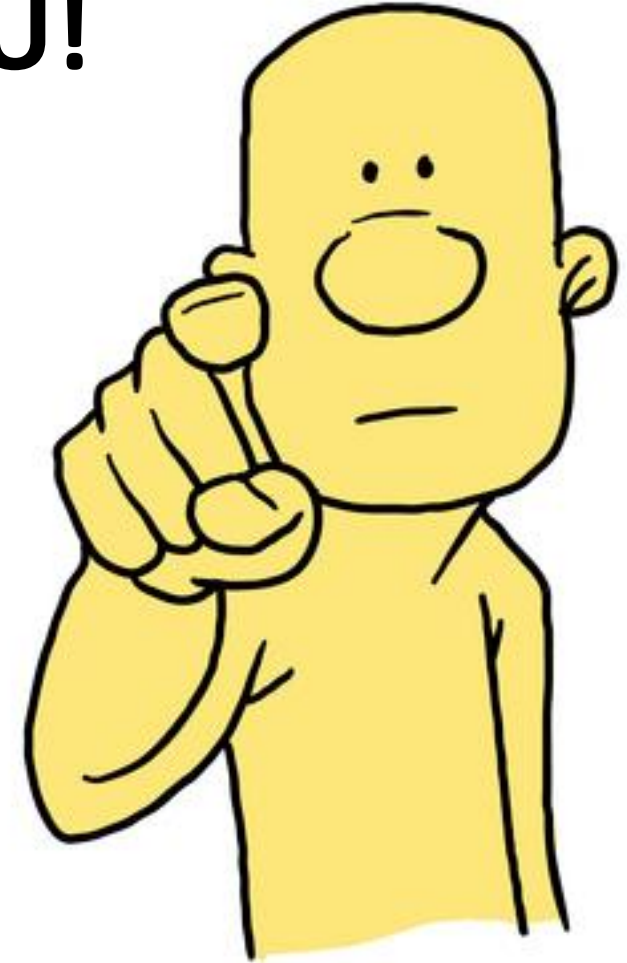
IT STARTS WITH YOU!

(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

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"

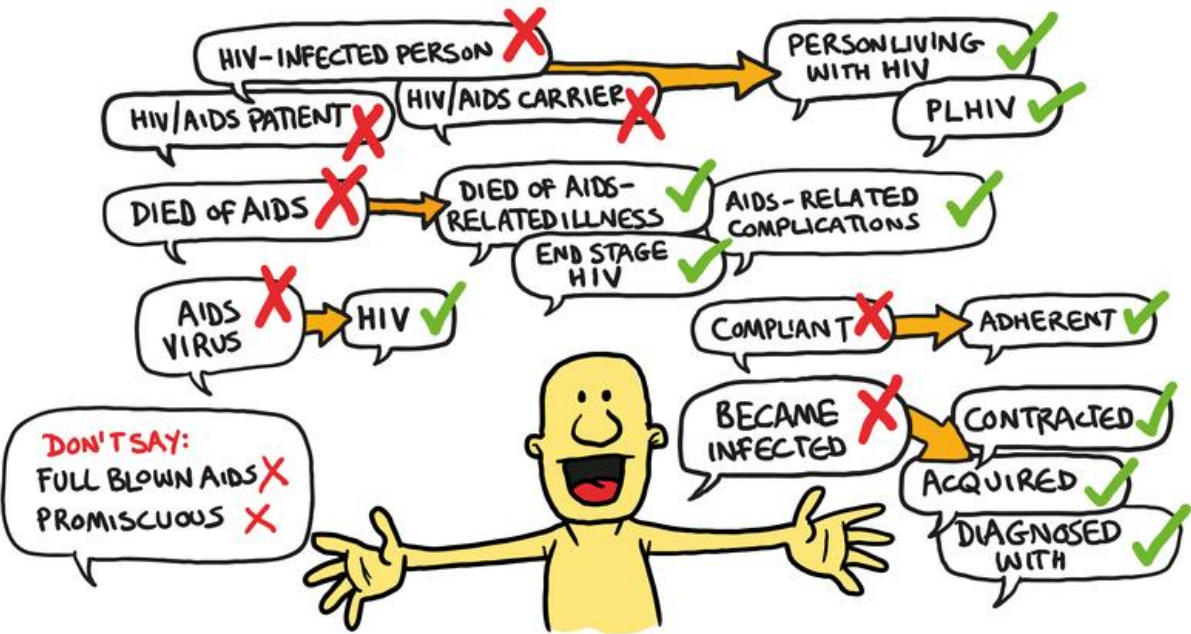Source: IAPAC Caliber of Care Stigma Dialogue Navigator

LANGUAGE MATTERS!
(CONTINUED)
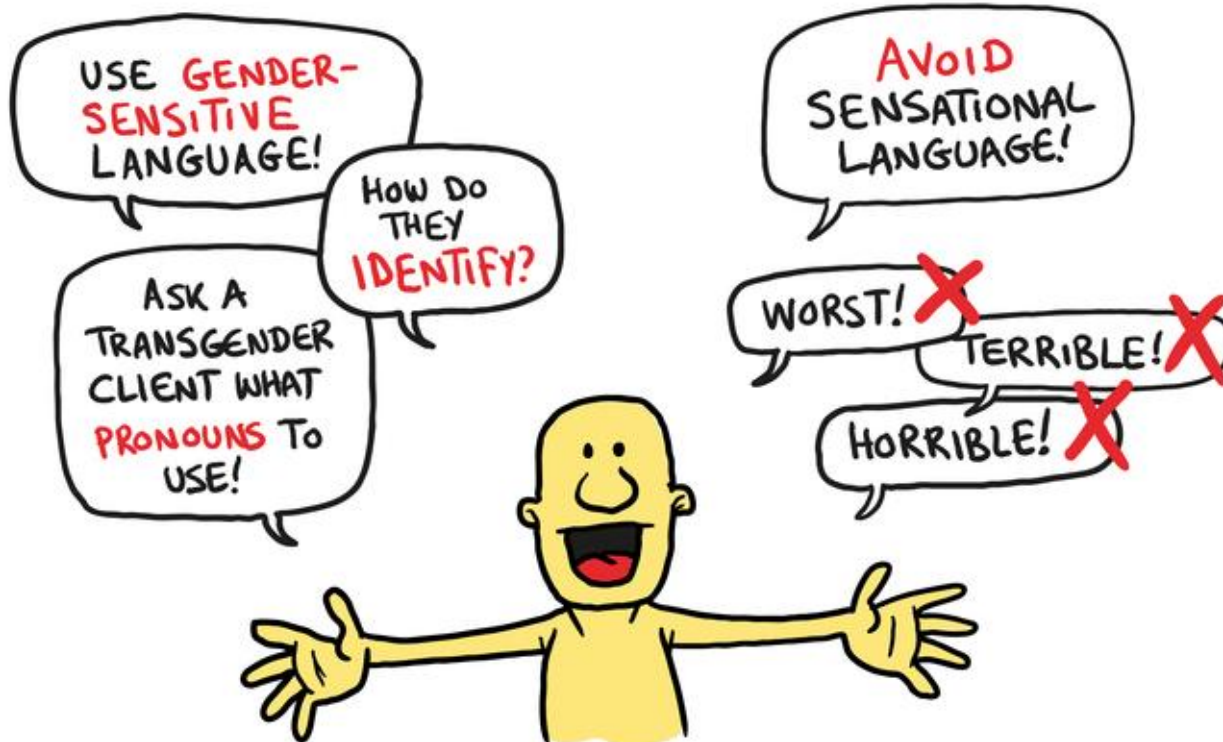
- Ask your patients how they identify & what they wish to be called

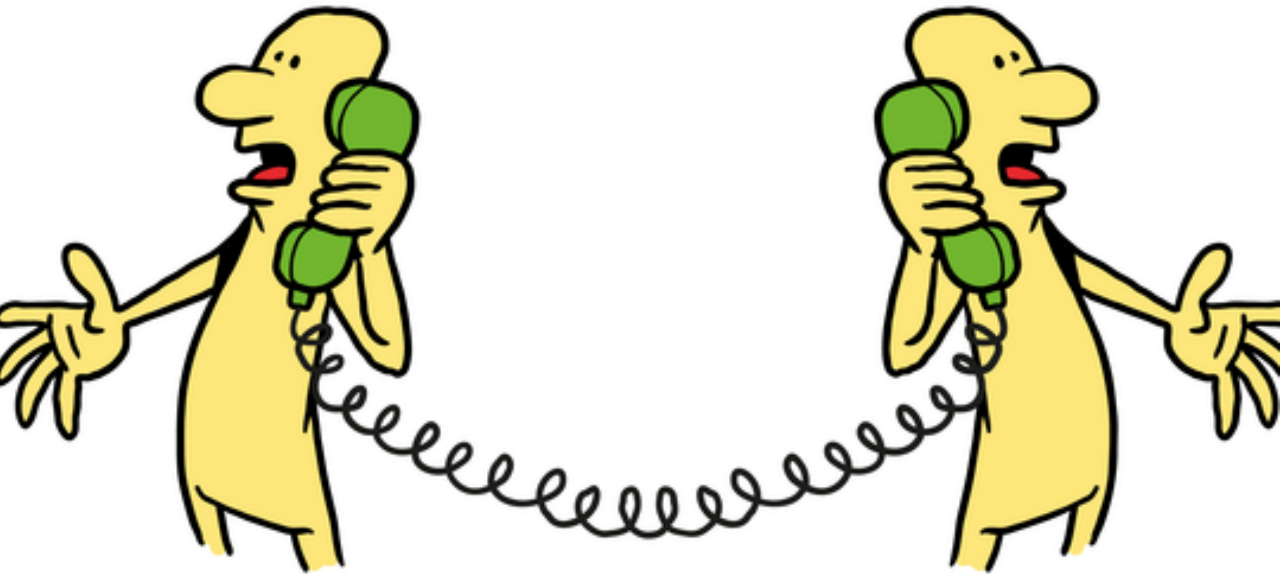- Use gender-sensitive language

- Avoid using sensational language

Source: IAPAC Caliber of Care Stigma Dialogue Navigator

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SAY THIS, NOT THAT!

Source: IAPAC Caliber of Care Stigma Dialogue Navigator

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	There is no medical definition for this phrase; simply use the term AIDS
Became infected with HIV	Acquired HIV
Compliance, compliant	Adherence, adherent
Promiscuous	This is a value judgment & must be avoided. Use "multiple partners"

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TWO-WAY LINE OF COMMUNICATION
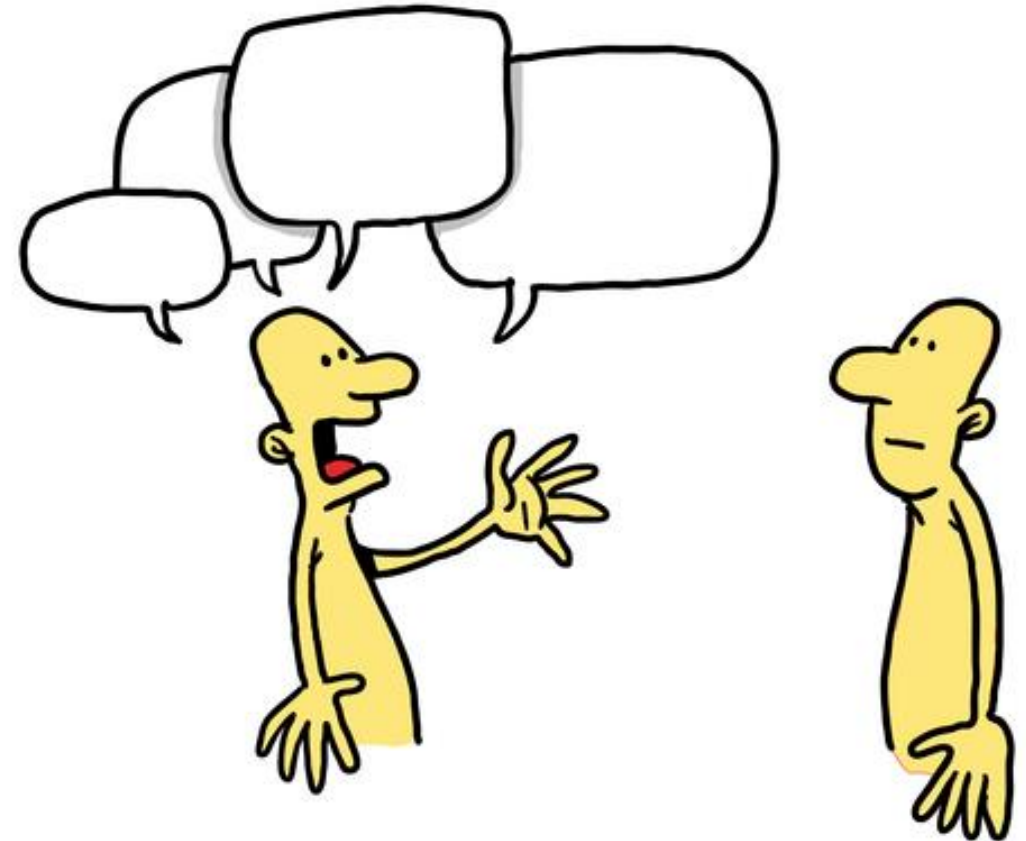
Source: IAPAC Caliber of Care Stigma Dialogue Navigator

"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

Adapted from "Everyone Has a Story: A Collection of Women's Stories and Conversations of Survival and Leadership" (SisterLove)

CONVERSATION STARTERS

- "I know experiencing stigma and discrimination can be at times very painful."

- "You are in a safe and 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."

Source: IAPAC Caliber of Care Stigma Dialogue Navigator

TREAT BY EXAMPLE

Treat HIV the same as you would any other medical condition

Establish eye contact

Avoid judgmental body language

Give your undivided & uninterrupted attention

Setting the tone will help people feel comfortable voicing challenges they have related to their care

Source: IAPAC Caliber of Care Stigma Dialogue Navigator
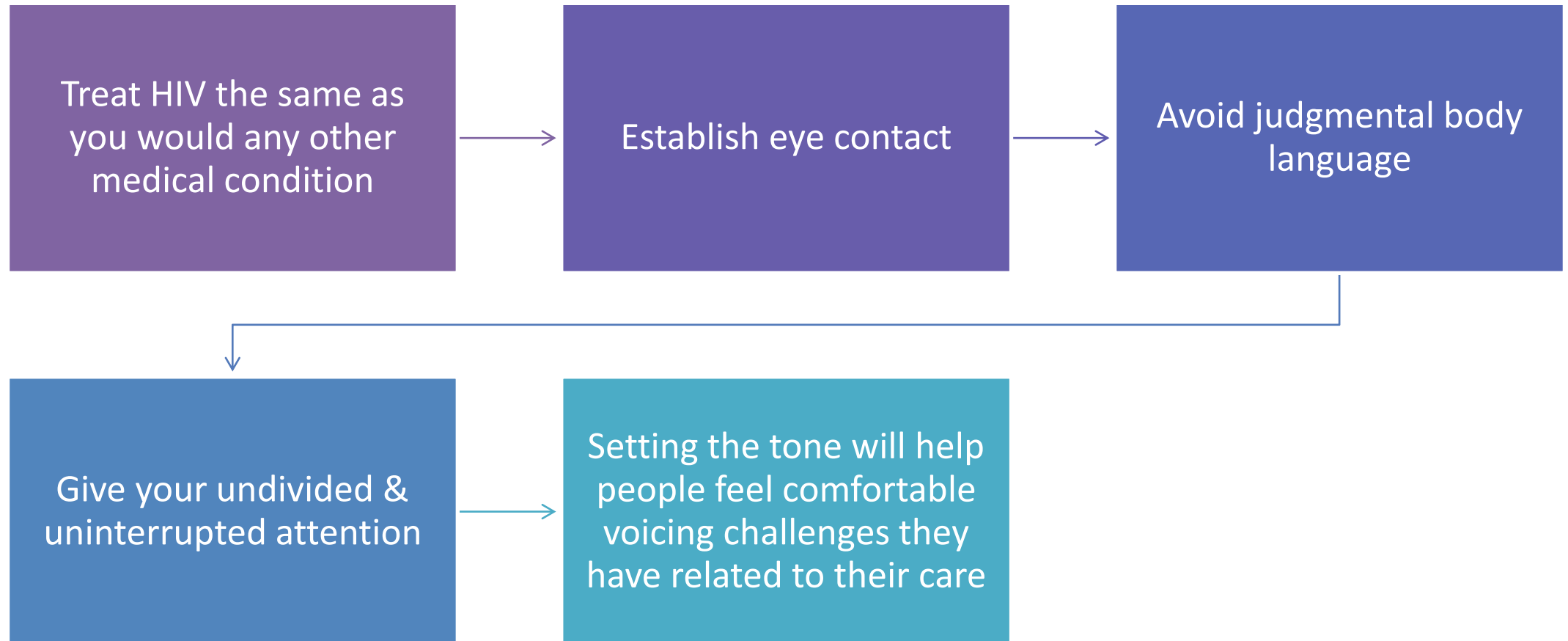
TREAT BY EXAMPLE (CONTINUED)

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

Source: IAPAC Caliber of Care Stigma Dialogue Navigator

**Eliminating Stigma & Discrimination in
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KEEP A PULSE ON YOUR COMMUNITY

1

Keep a pulse on the community where you practice

2

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

3

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

Adapted from the Health Policy Project

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 and 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)

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

- Undetectable = Untransmittable (U=U) conveys evidence-based message that <u>people living with HIV who achieve undetectable viral load cannot transmit HIV</u>
  - Talk to your patients about U=U and the:
    - Necessity of staying undetectable for U=U to work
    - Importance of HIV treatment adherence to stay healthy & prevent transmission
  - Explain and reinforce to your patients that when HIV is suppressed they will not transmit HIV to partners
  - Encourage them to know their viral load by keeping medical appointments so they & their partners are sure of their undetectable status

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NON-DISCRIMINATION IS A CORE HUMAN RIGHTS PRINCIPLE

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

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 and 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 contribute to protect and realize the human right of your patients to health services, including HIV, that are free of stigma and discrimination?

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 Martín Fisher Foundation (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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