

YOUR GUIDE TO CREATING A STIGMA-FREE HEALTH-CARE ZONE

TARGET AUDIENCE: Health-care providers, staff, and administrators at hospitals, urgent care centers, clinics, testing centers, and other settings that serve people living with HIV.

WHAT IS HIV STIGMA?

The CDC defines HIV stigma as "negative attitudes and beliefs about people with HIV...the prejudice that comes with labeling an individual as part of a group that is believed to be socially unacceptable." Stigmatizing behaviors in health care can take on many forms, from discrimination (i.e., refusing to take a person living with HIV as a patient) to using stigmatizing language (saying "HIV infection" instead of "HIV transmission," or calling patients "non-compliant" vs. "non-adherent.")

In many cases, a health-care worker may not even realize that what they are doing is harmful—or that their interpretation of an everyday interaction at the reception desk or in an exam room may have long-term psychological consequences for the patient and far-reaching public-health ramifications for the community.

WHY DOES HIV STIGMA MATTER?

The South is now the epicenter of the American HIV epidemic, home to the largest percentage of undiagnosed people living with HIV in the country, along with the highest HIV transmission and mortality rates. San Antonio is one of its hot spots: In 2016, Bexar County had the largest cluster of new HIV cases in the nation.

It doesn't have to be this way. We have the tools and medications to end the HIV epidemic right now. When taken as prescribed, PrEP (pre-exposure prophylaxis for HIV) can reduce the risk of someone contracting the virus by 99%. And in many people living with HIV, antiretroviral therapies can decrease viral loads to undetectable levels. **Undetectable equals untransmittable**, meaning those with fully suppressed viral loads cannot pass the virus on to their partners through sex.

To end HIV, we will need to increase testing, improve linkage to care, and ensure long-term engagement in care. HIV stigma makes achieving all of the above more difficult. Those living in communities where HIV stigma is the norm may begin to internalize and anticipate that stigma, which may lead to a reduction in preventative behavior, avoidance of testing, or decreased engagement in care. Cultural stigma may be especially pronounced in African-American and Hispanic communities, which have been disproportionately affected by the HIV epidemic.

Some research suggests that when a patient perceives bias in a health-care setting, it may affect engagement in care more profoundly than any other source of HIV stigma. In contrast, positive relationships with physicians are associated with increased levels of engagement in care. By eliminating HIV stigma in your hospital, clinic, or testing center, you may help improve not only your patients' outlook and well-being but also your own patient retention and outcomes.

UNDETECTABLE=UNTRANSMITTABLE
(U=U)

HOW DID WE CREATE THESE GUIDELINES?

When the Center for Disease Control (CDC) named San Antonio as the city with the largest cluster of new HIV infections in the U.S., a coalition of patient advocates, city public-health officials, people living with HIV, and academic medical centers came together to form the End Stigma End HIV Alliance (ESEHA). As part of San Antonio and Bexar County's efforts to end the epidemic, ESEHA made reducing HIV stigma one of its top public-health priorities.

ESEHA invited members of the HIV community to share their experiences with stigma in anonymous journals, formal interviews, and a live HIV storytelling performance. ESEHA also surveyed and interviewed San Antonio health-care workers to determine the main drivers and facilitators of health-care-related HIV stigma. The survey and focus groups identified several, including:

- knowledge gaps among health-care workers about the effectiveness of preventative drugs like PrEP and modern antiretrovirals
- discomfort or lack of knowledge about avoiding stigmatizing language
- fear of infection
- intolerant workplace cultures
- stereotypes and discriminatory attitudes toward people living with HIV, as well as groups at risk for HIV, such as LGBTQIA patients and injectable drug users

"At some clinics and doctors' offices, the receptionist can be very rude... I always speak up but there are a lot of clients who cannot do this...The receptionist is usually the first person they come in touch with, and if they don't feel respected, they may just walk away and we will lose them."
 —HIV educator/person living with HIV

Guidelines structure

ESEHA's Stigma-Free Health Care Taskforce, made up of clinicians, HIV advocates, and people living with HIV, used these research findings to develop evidence-based anti-stigma guidelines for health-care settings. Created by and for people living with HIV, these guidelines target health-care-related stigma on three levels:

- 1 INDIVIDUAL LEVEL**
 In health care, every person and every interaction have the power to reinforce or refute HIV stigma.
- 2 WORK-CULTURE LEVEL** From the operating room to the boardroom, health-care leaders must lead by example to cement an anti-stigma culture in the workplace.
- 3 ORGANIZATIONAL LEVEL**
 Long-term shifts in norms require procedural and systemic change



WHAT YOU CAN DO

EVEN THE SMALLEST ACTIONS CAN HAVE A HUGE IMPACT

When people walk into an HIV testing center or a clinic, they carry with them stigmatizing messages from the media, their faiths, and their communities. Any interaction that reinforces this stigma can make it less likely that they will return for regular testing or remain engaged in care. Here are some things you can do as an individual to help create a stigma-free health-care zone and foster an environment of acceptance and inclusivity.

| GOAL | GETTING THERE | DOS AND DON'TS |
|---|--|---|
| Encourage testing and reduce the trauma of diagnosis | Educate patients about the manageability of living with HIV starting from the first visit. Do take a thorough sexual history once, then ask for updates only on following visits. (No need to repeat questions that have already been asked and answered.) | <ul style="list-style-type: none"> • Do use judgment-free phrasing when taking a sexual history. (For example, ask clients if they are "having condomless sex" rather than if they "always use condoms.") • Don't celebrate negative tests or convey anxiety about positive ones. Inform clients of their results calmly and directly, offering empathy and support however they react. |
| Counteract stigmatizing messages from patients' families, cultures, and communities | Many people internalize the message that an HIV diagnosis makes them tainted or dirty; steer clear of any expressions that reinforce this perception. | <ul style="list-style-type: none"> • Do tell people when their viral load is undetectable (remember, U=U!). • Don't tell patients that they are "clean" if they test negative or are virally suppressed. |
| Show your patients that you see them as more than their diagnosis | Treat patients with respect using "people-first" language. That goes doubly for patients who also belong to other stigmatized groups, such as LGBTQIA people or people who use IV drugs. | <ul style="list-style-type: none"> • Do say "person living with HIV" or "person with a substance-use disorder." • Don't use dehumanizing terms like "HIV patient," "HIV infected," "HIVer," or "drug abuser." |
| Make patients feel comfortable and safe in the exam room | Alleviate any anxiety you may have about contracting HIV by educating yourself about how the virus is transmitted. | <ul style="list-style-type: none"> • Do follow standard safety protocols. • Don't double-glove, wipe down patients' seats, or avoid patient contact. |
| Encourage people to stay or re-engage in care | Refrain from shaming patients who miss appointments or don't adhere to medication | <ul style="list-style-type: none"> • Do welcome patients back to treatment. • Don't lecture or fine patients who miss appointments. |



WHAT YOUR WORKPLACE CAN DO

EVERYONE CAN MAKE A DIFFERENCE

Transforming the culture of a clinic or emergency room is not just about changing the behavior of providers. The words and actions of every person—from the environmental services technician to the office manager—can make the difference between a patient who comes to their next appointment and one who is lost to care.

CREATE A SHAME-FREE ZONE

Often with good intentions, providers use shame to motivate their patients. Unfortunately, not only is shame an ineffective way to change behavior, it can also exacerbate internalized HIV stigma, reduce adherence to treatment, and discourage engagement in care. So instead of asking "Why did you miss your appointment," when a patient calls to reschedule, try "We missed you yesterday. Is everything OK?"

NAMES AND PRONOUNS MATTER

Using patients' correct pronouns and names should become part of your work culture. Transgender women who have sex with men are at high risk for HIV. When they walk into a testing center or a doctor's office, they face both HIV stigma and trans stigma. Being asked their pronouns or how they would like to be addressed signal that they will be treated with respect during their care.

"The owners are gay and so the culture's been...how you choose to live your life, everyone has a right to healthcare... Their philosophy is we have to all be committed to excellence."

—Non-licensed health-care professional

A STIGMA-FREE WORK CULTURE BEGINS AT THE TOP

A good team leader or employer leads by example. Treating patients with respect by using people-first, non-stigmatizing language can go a long way toward inspiring the people around you to do the same.

KEEP ONE ANOTHER ACCOUNTABLE

In health care, many stigmatizing behaviors come not out of ill intentions but lack of knowledge. So if you notice a colleague using stigmatizing language, create a culture of accountability by speaking up. Just remember: Shame is an ineffective way to change behavior, so keep it positive and judgment-free.

EMPOWER YOUR PATIENTS

When it comes to retaining people living with HIV in care, relationships and respect matter. By making shared decision-making and collaborative patient-centered care the norm at your site, you will help engage your patients in their own health and help empower them to speak up when they encounter stigma in other health-care settings.



WHAT YOUR ORGANIZATION CAN DO

Making changes on an individual or workplace level is not enough. Procedural and structural interventions are required for anti-stigma practices to become enduring norms.



1 FORMALIZE ANTI-STIGMA TRAININGS

Many stigmatizing behaviors come from fear or knowledge gaps. Implement judgment-free annual trainings that cover people-first language, safe-space guidance, harm reduction, evidence-based safety protocols, and the public-health ramifications of HIV stigma.

2 PRIORITIZE PEER SUPPORT AND WARM HAND-OFFS

People living with or being tested for HIV are not treated by one provider or even one organization. Many endure the trauma of a diagnosis without immediate support or prompt linkage to stigma-free care. Organizations should make use of patient navigators to guide people living with HIV through the process with compassion and ensure that any referrals made outside the organization are to health-care providers with anti-stigma practices in place.

3 CREATE PROCESSES THAT ENCOURAGE SINGLE-CAPTURE HISTORIES

People living with HIV often have to endure intrusive questions about their how they contracted the virus, their sexual practices, and past drug use. Trans people must reaffirm their pronouns, their gender history, and hormonal regimen every time they visit an ER or clinic. Customizing EMRs to capture gender and sexual history on the first visit eliminates the need to re-traumatize patients every time they walk in the door.

4 RETHINK THE RULES

Some funding programs and testing centers require that providers take a new sexual history at every visit. That means clients must overcome their dread of invasive questions each time they visit. Re-examine procedures and regulations that might make people less likely to seek or remain engaged in care.

5 PROMOTE TRAUMA-INFORMED CARE

Along with the trauma of diagnosis, many people from historically marginalized groups—who are often disproportionately affected by HIV—are also dealing with other traumas, including racism, homophobia, sexual assault, and physical abuse. Create a trauma-informed health-care environment that prioritizes patients' safety and comfort, builds trust, and meets patients where they are.

6 BUILD IN ACCOUNTABILITY

Assessing a new procedure or system requires measurable data and regular evaluation. This will allow you to gauge what's working, what isn't, and what additional structural changes need to be made to create a true stigma-free health-care zone.