



**AETC** AIDS Education &  
Training Center Program  
**Southeast**

# Person-Center HIV Care Critical Strategies to Improve Retention and Engagement

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## Learning Objectives

After attending this program participants will be able to:

1. Explain the term *Person Centered Care* as defined by the Institute of Medicine (IOM).
2. Explain the terms *cultural humility* and *cultural safety* and discuss ways that healthcare professionals practice these activities when providing care to people with HIV (PWH)..
3. Identify the purposes of communication and the direct and indirect ways that communication influences patient healthcare experiences.
4. Name and demonstrate two(2) communication strategies that create opportunities for clients to feel empowered, engaged and connected to their providers and healthcare teams.

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## Agenda



Welcome and introductions

Person-centered care and patient experience

Cultural humility and safety

Patient experience

Health Literacy and HIV

Communication pathways

Communication strategies

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## Healthcare Hero “Backpack” Activity



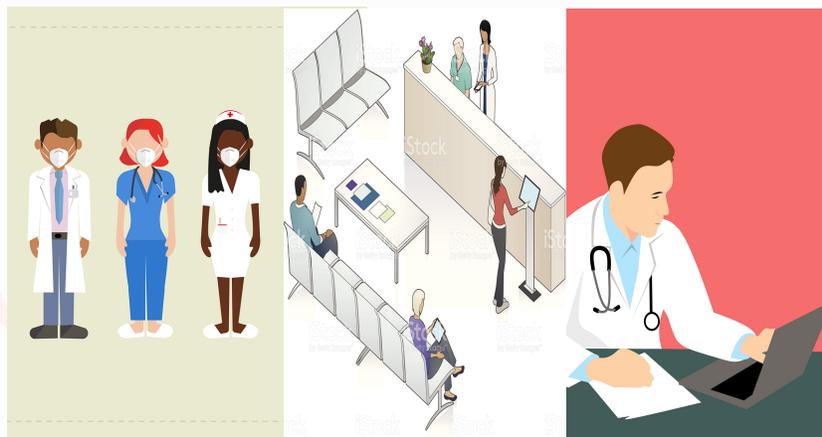
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## Healthcare Hero Zoom Room Travel



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## Key Healthcare Hero Strengths



## Patient Experience

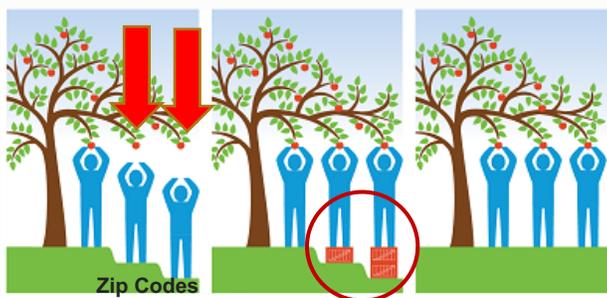
### LINKAGE AND RETENTION IN HIV CARE

Welcome!  
How Can I Care for You Today?



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## Health Equity

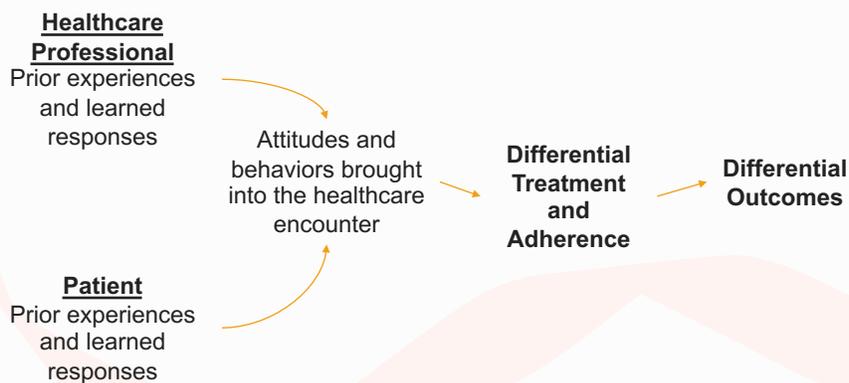


### Healthy People 2020

“The attainment of the highest level of health for all people.”

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## How Do Health Encounters Result in Different Health Outcomes?



Source: Blair IV, Steiner JF, Havranek EP. Unconscious (Implicit) Bias and Health Disparities: Where Do We Go from Here? *The Permanente Journal*. 2011;15(2):71-78.

*“...providing care that is respectful of and responsive to individual patient preferences, needs and values, and ensures that patient values guide all clinical decisions.”*

## Person-Centered Care



- Institute of Medicine Crossing the Quality Chasm: A New Health system for the 21<sup>st</sup> Century (2001)



## Person-Centered Care

- Honors the patient's right to decide
- Involves shared decision making
- Individualizes care
- Personalizes care

- Respectful
- Genuine
- Transparent
- Nonjudgmental

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## The Role of **CULTURE**

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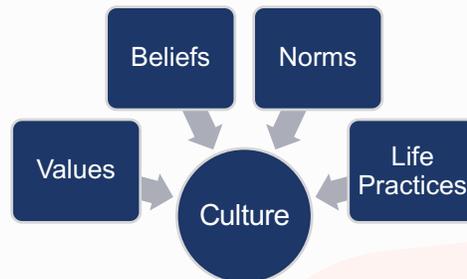
## What Culture is Not

- Personality
- Static
- Spoken language
- Ethnicity or racial identify
- Gender identification
- Geography



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## Culture

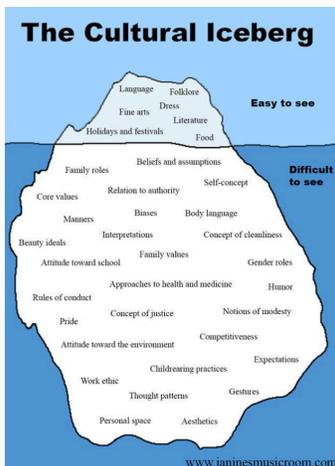


**Culture is the lens through which people view and attach meaning to health communication.**

(IOM, 2004)

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# Culture is Everything About Us



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# Chicken Soup



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“People live in a context. The context is their life. It often starts before their birth and goes across their entire lifetime. Unless we understand this, we often miss an opportunity to help another human...”

## Cultural Caring

Dr. Helen L. Erickson  
Nurse Theorist



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### Cultural Caring Sex & Gender Identity

Sex vs Gender What's the difference?

- Classification: male or female
- Feminine vs masculine continua
- Gender (social) is not interchangeable with sex (biological)



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## Gender is Different Than Sexual Orientation

- **Sex is biological**
- **Gender identity is personal** (how we see ourselves)
- **Sexual orientation is interpersonal** (who we are physically, emotionally and/or romantically attracted to).
- When we confuse gender with sexual orientation, we often make assumptions about a person that have nothing to do with **who they are**
- **Gender expression is about what a person wears-** a person's sexual orientation cannot be determined by what they have on

## Cultural Proficiency

Cultural proficiency is the knowledge, skills, attitudes, and beliefs that enable people to work well, respond effectively to, and be supportive of people in cross-cultural settings.

Healthcare professionals care for a wide variety of patients and need cultural proficiency skills to improve patient care.

Reference: American Academy of Family Physicians. Cultural Proficiency: The Importance of Cultural Proficiency in Providing Effective Care for Diverse Populations, updated 2014. Leawood: American Academy of Family Physicians; 2014: Position Paper.

## Cultural Proficiency

- Is more than acceptance of cultural differences
- Ensures that care and services are responsive to the cultural and linguistic needs of all individuals
- Adheres to the National Standards for Culturally and Linguistically Appropriate Services (CLAS)



American Academy of Family Physicians. Cultural Proficiency: The Importance of Cultural Proficiency in Providing Effective Care for Diverse Populations, updated 2014. Leewood: American Academy of Family Physicians; 2014: Position Paper.

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“...the ability to maintain an interpersonal stance that is other-oriented (or open to the other) in relation to aspects of cultural identity that are most important to the [person].”

## Cultural Humility



Hook, J. N. et al (2013). Cultural humility: Measuring openness to culturally diverse clients. *Journal of Counseling Psychology*<sup>®</sup>, 60, 353-366.

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# Cultural Humility Concept Model



## Behaviors

- Openness
- Self-awareness
- Egoless
- Compassion
- Supportive Interaction
- Self-reflection and critique

# Gender Affirming Care

**Do Ask, Do Tell**

Talk to your provider about being LGBTQ. Your provider will welcome the conversation. Start today!

### ACCESO A ATENCIÓN Y RECURSOS

Hay muchos recursos para pacientes LGBT que buscan atención y asesoramiento médico. Aquí hay algunos en los que podría estar interesado:

- ¿Dónde está la información sobre atención médica y genética LGBT? El centro de educación de salud sexual (CES) tiene publicaciones y recursos para pacientes y proveedores. [www.gilead.com/education](http://www.gilead.com/education)
- ¿Dónde está la información sobre temas de salud de personas transgénero? El Centro de Recursos para la Salud de personas transgénero (CRST) ofrece recursos. [www.transhealth.org](http://www.transhealth.org)

• ¿Dónde está la información sobre organizaciones de atención médica que brindan un asesoramiento que incluye atención LGBT? El departamento de atención humana (PHC) publica un directorio en línea de servicios de salud. [www.phc.org](http://www.phc.org)

• ¿Dónde están los recursos para sus amigos o familia? Puede ayudar a personas lesbianas y gay (PLGA) a publicar listas de organizaciones de apoyo, educación, y defensa. [www.lgbt.org](http://www.lgbt.org)

### PREGUNTAS MÁS FRECUENTES

• ¿No quiero que sepa más que mi proveedor que soy gay o lesbiana? ¿Debería ocultarlo? No, no debería. Compartir su identidad sexual con su proveedor de atención médica puede ayudar a que se sienta más cómodo al discutir temas como la prevención de infecciones de transmisión sexual (ITS) y el uso de preservativos. Si no quiere revelar su identidad sexual, puede decirle a su proveedor que "tiene una orientación sexual diferente a la de la mayoría de la gente".

• ¿Qué sucede si mi proveedor me pregunta si soy gay o lesbiana? No se debe sentir obligado a responder. Si quiere, puede decirle que "tiene una orientación sexual diferente a la de la mayoría de la gente".

• ¿Qué sucede si soy un proveedor de atención médica? No se debe sentir obligado a revelar su identidad sexual. Si quiere, puede decirle a su proveedor que "tiene una orientación sexual diferente a la de la mayoría de la gente".

• ¿Qué sucede si soy un proveedor de atención médica? No se debe sentir obligado a revelar su identidad sexual. Si quiere, puede decirle a su proveedor que "tiene una orientación sexual diferente a la de la mayoría de la gente".

### Pregunte y dígalos:

Hable con su proveedor de atención médica sobre ser LGBT.

## When Cultural Humility is NOT PRACTICED

People with HIV:

1. Do not show up for appointments
2. Are poorly retained and engaged in health care and prevention behaviors
3. Have poor health outcomes
4. Have shortened life spans

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## Using “People First” Language

“People first” language puts the person before their illness, disability, job or any aspect of their personality

A person is not their illness

Defining a person by their illness, ethnicity or life choices deprives the person of the opportunity to define him/herself

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## Cultural Humility is a Conscious Ongoing Process



Minimization



Self check-in



Awareness



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## Culture Informs Us It Does Not Separate Us

- Culture helps us learn what we have in common with others
- Learning about peoples' cultural background, including values, promotes **CULTURAL SAFETY**
- When healthcare professionals practice **CULTURAL SAFETY**, patients do better and have improved outcomes

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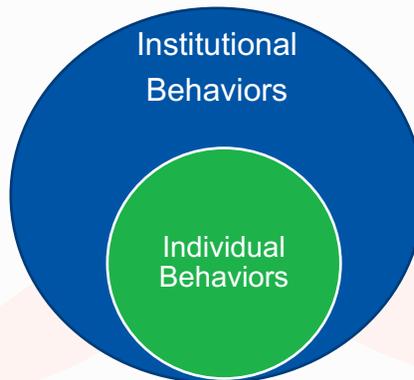
## Culture Herbal Use

Herb	Remedy/Treatment
Ginger Thomas	Tea from leaves and flowers treats colds, fevers, headaches, diabetes, jaundice
Hibiscus	Faded flowers in cough syrup
Lemon Grass	Flu and fever
Lignum Vitae	Leaves and flowers for debility; bark for fish poisoning
Lime Bush	Tea to take away upset stomach
Mints	Tea to treat stomach ache, dispel gas and mild laxative
Papaya	Seeds steeped for diabetes; leaves tenderize meat; green fruit crushed for bruises
Passion Fruit	Flower for eye tonic, tension, tension headache, high blood pressure
<b>Soursop</b>	<b>Tea used as sedative-sleep inducer; plug (center of fruit) for bedwetting</b>
Sorrel	Leaves with carrot tops and seeped to make tea for cooling and kidney or bladder ailments
THC Tetrahydro-cannabinol	Leaves are inhaled/ingested, seeped to make tea or extracted to make oil for inhalation or skin application; increases appetite, helps with sleep, anxiety and some types of pain

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## Cultural Humility Practice Behaviors

- Individual Behaviors
- Institutional Behaviors



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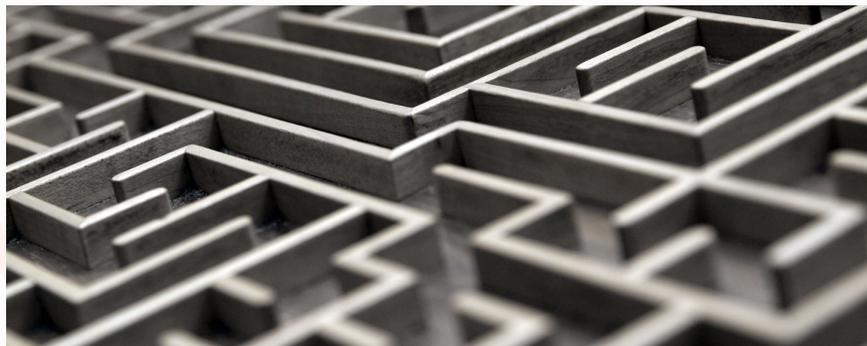
## What is Your Clinic Culture?



- Welcoming from the front door to the back door?
- What do patients think about your healthcare facility and programs?

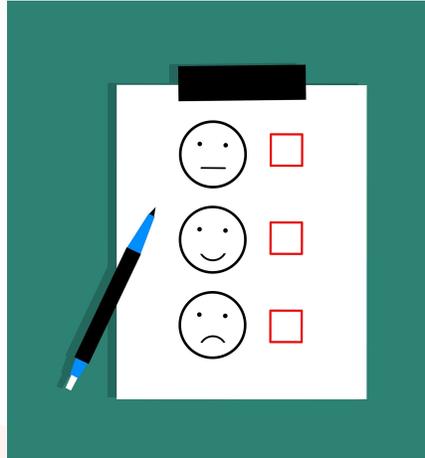
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## Disruptive and Confusing Times



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## What Do Consumers Think About Their Healthcare Experiences?



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## Consumer Health Experiences in HIV Care

Over 90% of patient complaints are about patient experience. Negative patient experience often causes a “break” in the patient-provider relationship resulting in some patients not showing up for in-person or virtual healthcare appointments.

The good news is that we can remedy this “break-up” and create better connections with our patients by conducting mystery shopper assessments.

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## Patient Experience

**Patient experience** is the “sum of all the interactions and experiences in the organization that influence the patient’s perceptions across the continuum of care. “

*Beryl Institute, 2017*

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## Florida HIV Quality Improvement Projects



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## Positive Feedback

“Made me feel that my concern to become eligible was important and that she would work with my concerns about privacy.”

“We spoke in English. She worked hard to understand my accent and checked in with me if she was unsure.”

“We had no interruptions. I felt like I had her full attention.”

“Jan\* was very good and provided me with information that I didn’t even have to ask for, which made me feel comfortable.”

\*names were changed

## Positive Clinic Experiences

“I walk out of my doctor’s appointment knowing my labs...CD4 count and viral load. It feels good to have my doctor talk with me about how I am doing.”

“The Case Manager was really great. I felt like I could talk to her about anything.”

“The staff that works with my provider is really good. They seem to really care about me.”

## Negative Clinic Experiences

"This experience at the front desk was **very confusing and frustrating** because they didn't seem to care about why I was there asking questions. I asked to see **someone in Outreach and when they** didn't understand that I asked to see a case manager so I could be linked to care. **The person asked me out loud if I was HIV-positive.**"

"I wish the provider wouldn't tell me how busy they are as they are walking in the room to see me. It makes me feel **rushed and less important.**"

"I felt that the **staff were biased about my age.** I think they believed I was young, immature and incapable of following directions."



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## Negative Feedback

"Called twice and reached voicemail. Automated menu was in...very basic Spanish."  
—*Spanish-speaking participant*

"Kept repeating things in English and grew **very frustrated.**" —  
*Spanish-speaking participant*

"They were completely silent, and I felt like I had to explain why I was calling without them responding or asking any questions."

"Never reached helpful contact."

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## Positive Telephone Experiences



“I had the attention of the person on the phone. I **felt important.**”

“I like the automated **appointment reminder calls.**”

“A nice **friendly person** answered the phone.”

## Negative Telephone Experiences



“They asked me my birthday. I said 2-1-92 day-month-year. They said I wasn’t in the system. I corrected myself and gave month-day-year. Someone in the background laughed and said, ‘who doesn’t know their own birthday?’ I felt demoralized and hung up.”

“I kept getting a voice message when I called that said to leave my name and number and that someone would call me back. I didn’t want to leave my name on a message machine. I wanted to talk to someone. Besides, I don’t have my own phone.”

Image accessed at <https://pixabay.com> on 10.23.2020

## Additional Reported Negative Telephone Experiences

"I was transferred 4 times before getting to the right person to make an appointment. I **wanted to just hang up after the second transfer.**"

"It was after Christmas and before December 30th and I wanted to find out how to see a provider. I kept getting voice mails. The recorded message didn't say what the holiday hours were so I **didn't know when to call back.**"

"I **had to have a lecture** by the desk staff about how I had to first have my HIV test results before I could see anyone even if I was testing several years ago. This **all occurred in the waiting room lobby** got me upset. No one ever offered to take me to a private room to discuss this testing issue. I don't want to go back there."



## One Word Description of Phone Calls

informative  
terrible  
unhelpful  
overwhelming  
uncomfortable  
helpful  
adequate  
respectful  
disappointing  
friendly  
frustrating  
impersonal  
confusing  
comfortable  
circutous  
excellent  
rushed



## Client Experience Interviews

February through March 2020



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## Positive Feedback

“They were sweethearts” – regarding the eligibility front office staff

“I didn’t have my letter [of eligibility] and...we made a plan to get it” –regarding the eligibility worker

“Carly\* made me feel comfortable.” –regarding the eligibility worker

\*names have been changed



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## Negative Feedback

**“I was intimidated. Everyone looked extremely busy. I walked in the center, lost and confused.”**

**“There was a guy who wasn’t the nicest, but I don’t think he works there anymore so maybe ‘they’ picked up on that.”**

**“I was given a different colored folder than everyone else and that kind of made me feel paranoid.”**

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## Discussion

### What Alienates Patients from Our Clinics?



**Zoom Room  
Discussions**

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## Important Discussions for Organizations Committed to Improving Patient Care Outcomes

- All staff help to engage patients in care, especially the front desk staff
- Brief engaging messages from all staff are critical to helping patients feel safe and valued



## Building a Culture Focused on Customer Service

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**CUSTOMER SERVICE SHOULD NOT BE A DEPARTMENT, IT SHOULD BE THE ENTIRE COMPANY**

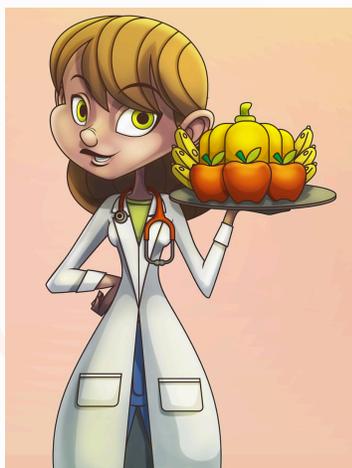
TONY HSIEH, CEO OF ZAPPOS

## Not This



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## Not This



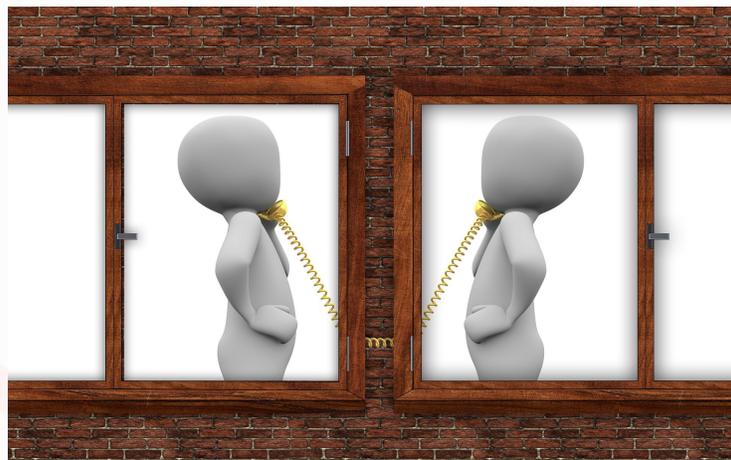
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## Yes! Use Neutral Terms

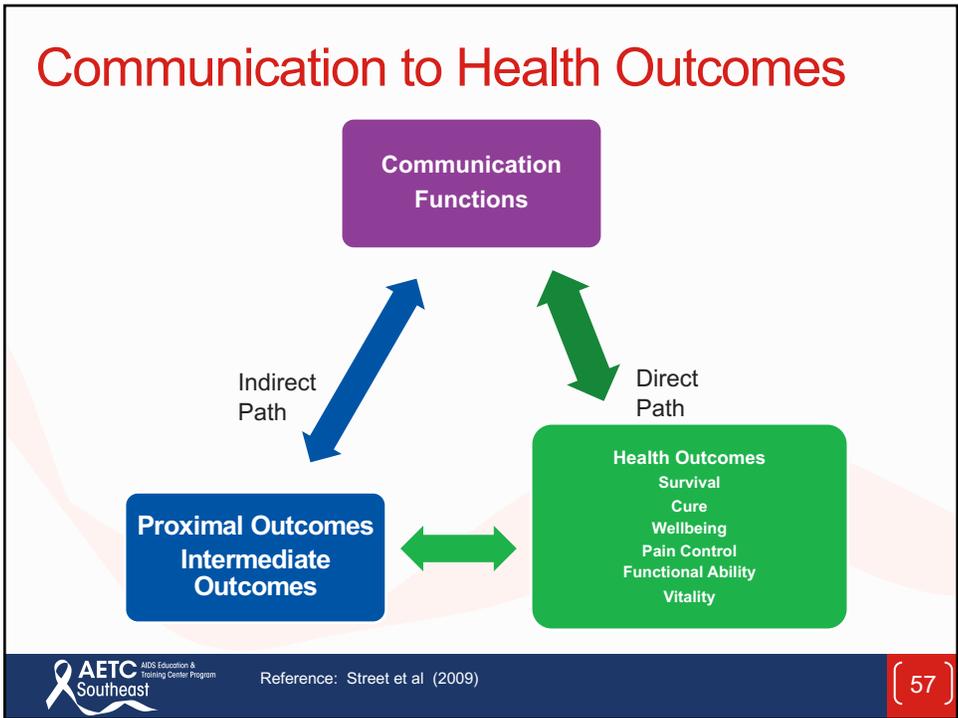
- **Substance use**  
(not ~~substance abuse~~)
- **A person who uses drugs, alcohol, or substances**  
(not ~~drug addict, drug abuser, alcoholic, junkie, crackhead, tweaker~~)
- **Negative or positive toxicology results, unexpected or expected**  
(not ~~"clean" or "dirty" toxicology results~~)
- **A person who formally used drugs or alcohol**  
(not ~~got clean~~)
- **A recurrence of use or "return" to use**  
(not ~~relapse~~)

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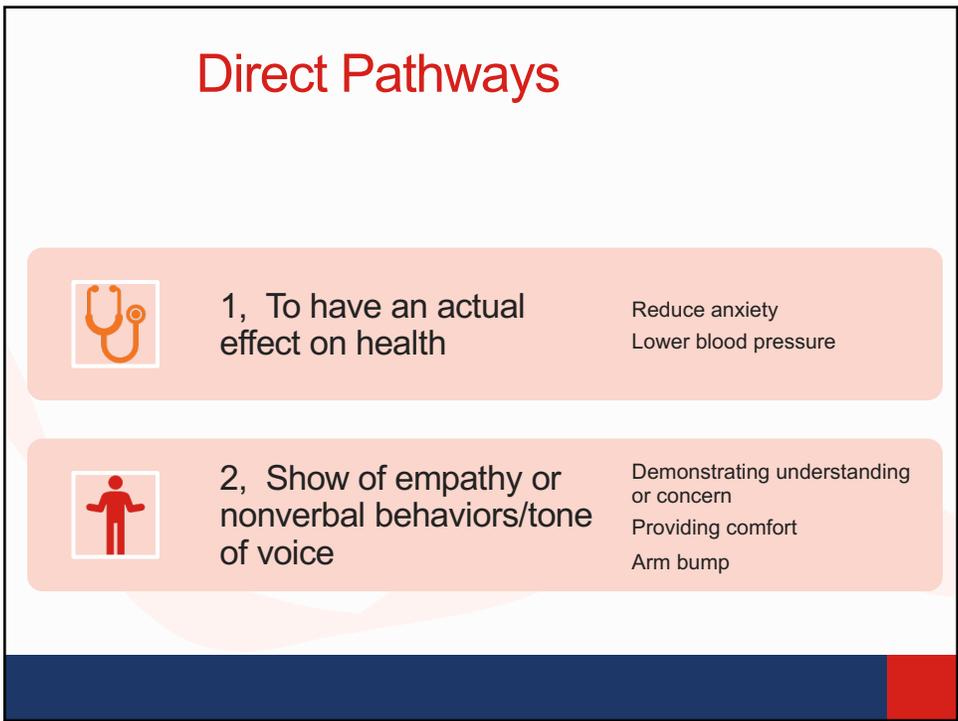
## Communication and the Patient Health Experience



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## Indirect Pathway

### Short term Outcomes

- Understanding
- Satisfaction
- Trust
- Empowerment
- Motivation

### Intermediate Outcomes

- Access to care: Know the next steps or how to access services
- Informed decisions
- Commitment to treatment: Medication adherence
- Can impact health outcomes

## Communication and Health Literacy

Health care professionals' awareness of health literacy can:

- Link and engage patients in care
- Help patients benefit from medical care and treatment
- Impact patient health outcomes



Health literacy further complicates health communication regardless of a patient's literacy level

## Definition of Health Literacy

### Expanding the definition

A **patient's ability** to obtain, understand and act on health information

A **provider's capacity** to communicate clearly, educate about health and empower their patients



Reference: Minnesota Health Literacy Partnership [healthliteracymn.org](http://healthliteracymn.org)

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## Brief Health Literacy Screening Tool

Four questions to detect inadequate health literacy levels:

1. How often do you have someone help you read prescription drug information or materials you receive from the doctor's office?
2. How confident are you in filling out medical forms by yourself?
3. How often do you have difficulty learning about a medical concern because of difficulty understanding medical information?
4. How often do you have difficulty understanding what is told to you about your medical condition?

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## Higher Health Literacy is Linked to Improved Medication Adherence

- Diabetes (Nandyala et al, 2018; Osborn et al, 2011)
- Hypertension (Heizomiet et al, 2020; Lor et al, 2019)
- Antidepressant medication (Bauer et al, 2013)
- **HIV (Kalichman et al, 2008; Wolf et al, 2007)**



Source accessed on 12/8/2020 at <https://www.avert.org/living-with-hiv/antiretroviral-treatment/what-does-undetectable-mean>

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## Use Teach- Back Method to Support Health Literacy



- “We have talked about a number of things today. Can you tell me about what you learned about how to take your new medication? I want to be sure my teaching was clear.”  
OR
- “When you get home after your appointment today, your partner may ask what we talked about. Can you tell me what you remember of what I said so I can be sure I gave you clear instructions?”



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## Strength-Based Approach to Care

### Strength-Based Approach

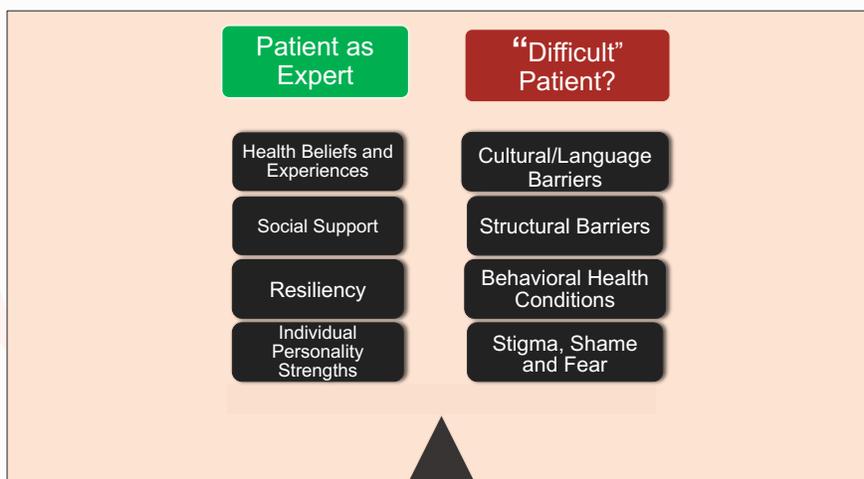
1. What happened to you?
2. What can you do right now?
3. What is possible?
4. How can we work together to improve your present and future health?



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## New Paradigm: Partnering with Patients



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## Providing Trauma-Informed Care

- Create a safe and sensitive environment
- Communicate sensitivity to individuals who have experienced traumatizing events
- Provide brief empathic responses to individuals who do report experiencing trauma
- Provide services in a trauma-informed manner



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## Use Open-ended Questions and Actively Listen to the “Expert” Patient

- “What is your biggest fear or worry right now?”
- “What matters most to you?”
- “How can we help?”
- “What’s the one thing that you want to be sure happens at your appointment today?”



**Active  
Listening**

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## The Significance of Nonverbal Communication

- **7% Verbal**  
(conveyed in words)
- **38% Vocal**  
(intonation, pitch, speed, pauses..)
- **55% Nonverbal**  
(body language)



Mehrabian, A. and Wiener, M. (1967). Decoding of inconsistent communications, Journal of Personality and Social Psychology, 6, 109-114

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## Everything Starts with the Patient

A patient doesn't care how much you know until they know how much you care (about them as a person).



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## Cultural Humility Acknowledges Patients as Experts in Themselves



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## Building Rapport Using ORCA

Openness-

Respect

Curiosity

Accountability



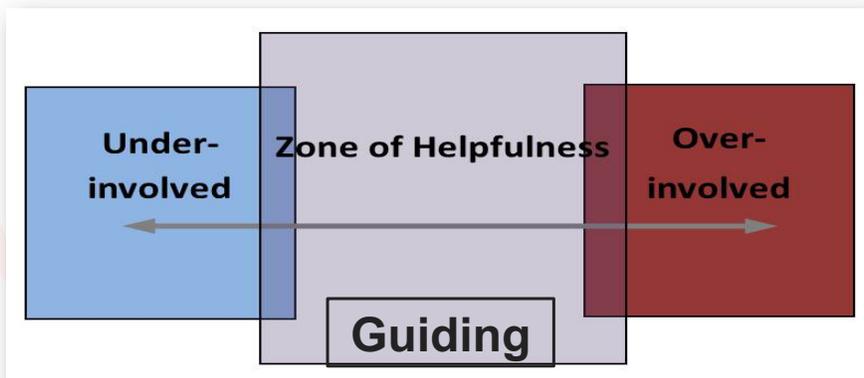
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## Guiding Versus Fixing



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## Empathy, Sympathy, Compassion and the Guiding Zone



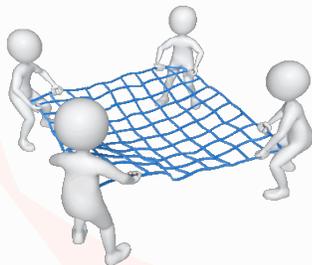
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## Creating a Welcoming and Accessible Healthcare Environment

- Every non-clinical and clinical staff member takes part in providing a culturally safe environment for our patients.
- Cultural humility, trauma informed care, compassionate communication and critical thinking are powerful tools that help to improve patient linkage and engagement in HIV care.
- Engagement in HIV care maximizes health outcomes for people with HIV.

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## Ask (and Listen) About What Matters So the Team Can Do What Matters



**“We want all our patients to stay connected to care”**

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Is this or could this be your healthcare team?



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What is your vision of cultural humility and cultural safety within your healthcare system?



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## Speaker Contact Information

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