

A photograph of a woman with long dark hair in a ponytail, wearing a black and yellow patterned top, sitting at a desk and talking to a male doctor. The doctor is wearing a white lab coat, glasses, and a stethoscope, and is gesturing with his hands while speaking. The desk is cluttered with papers, a red sharps container, and a smartphone. The background shows wooden cabinets and a white wall with some notices.

Addressing Low Retention Across Diverse Patient Populations

Presenters



Cecilia Gentili

Principal, Transgender Equity Consulting



Kristin Potterbusch

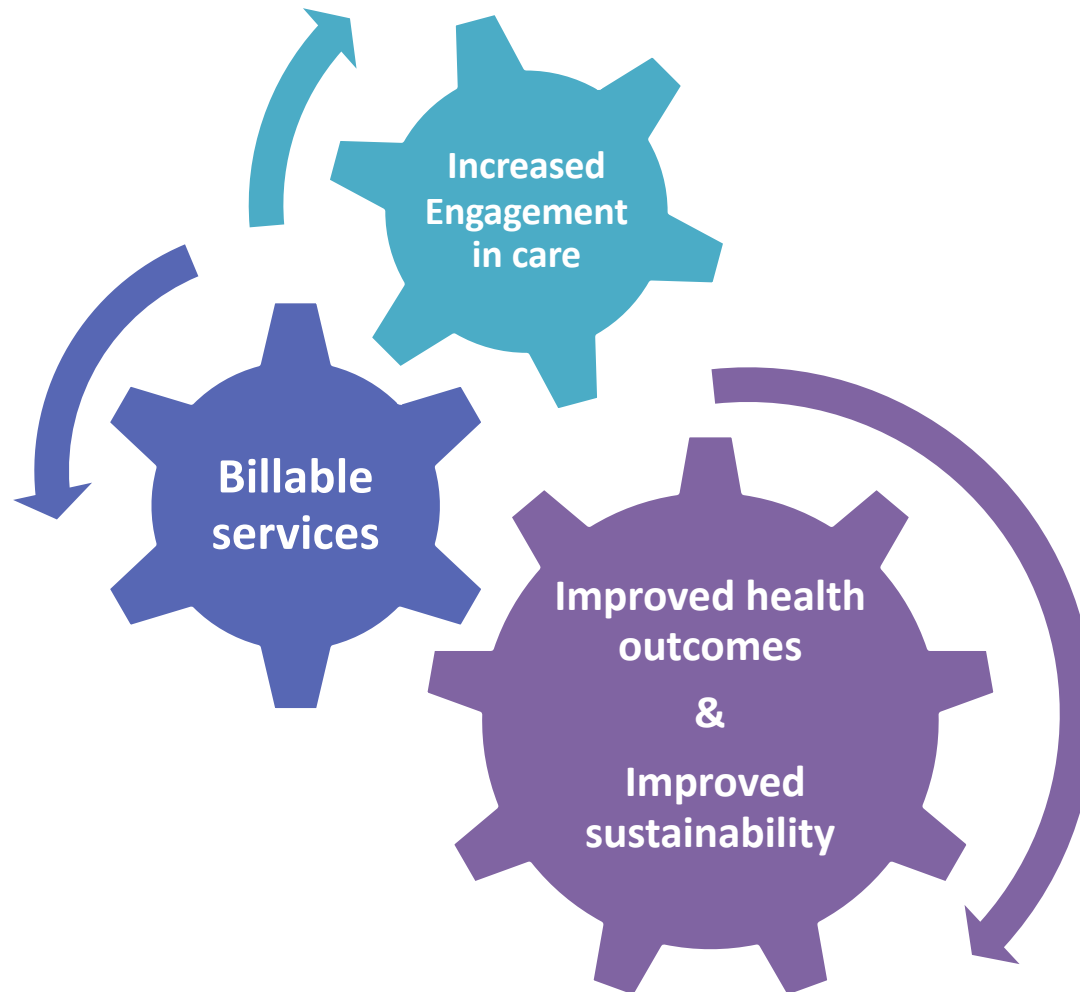
Program Director, PCDC

Poll

What's life like where you are viewing (check all that apply)?

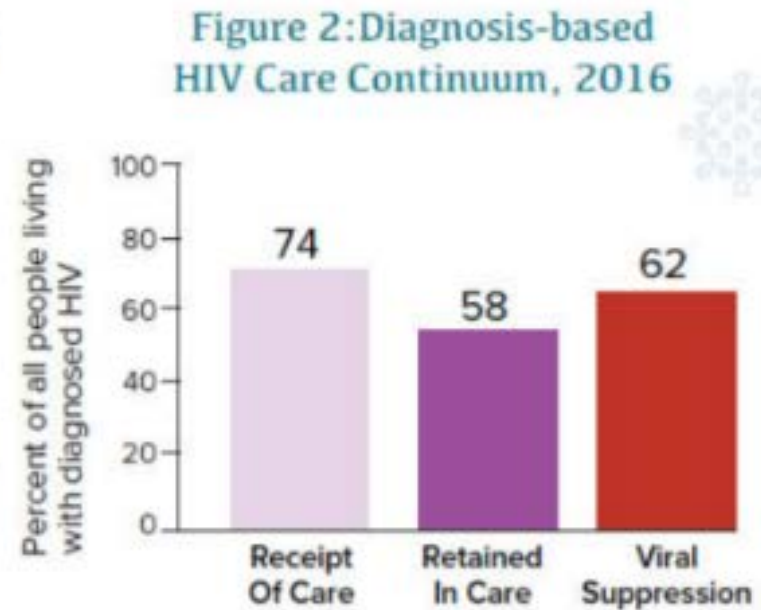
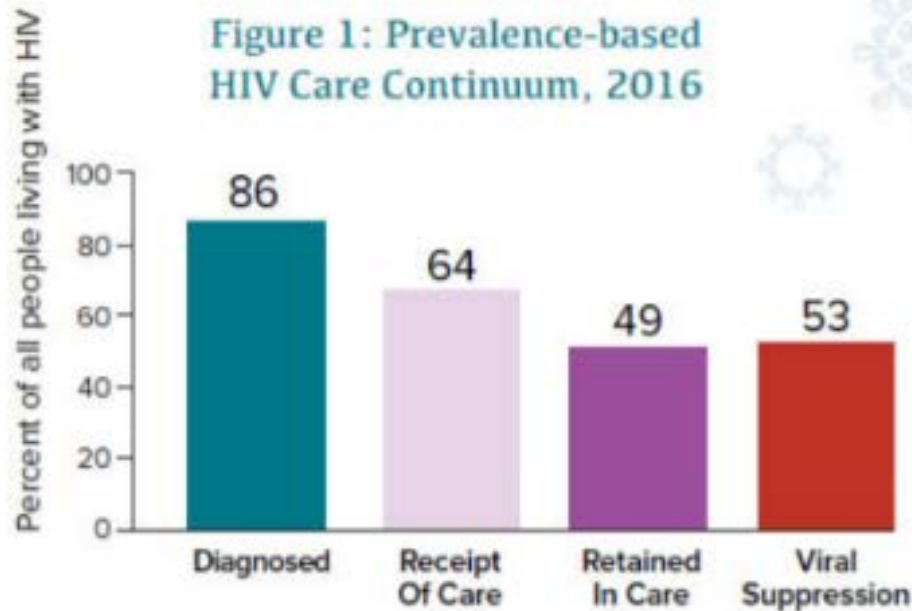
1. I'm in a clinical setting
2. I'm in a nonclinical office setting
3. I'm at home and otherwise normal
4. I'm at home, and helping care for children and others
5. Other

Retention in Care: A best practice with benefits

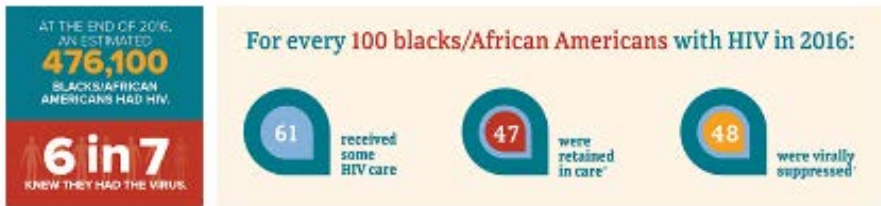


Where We Stand

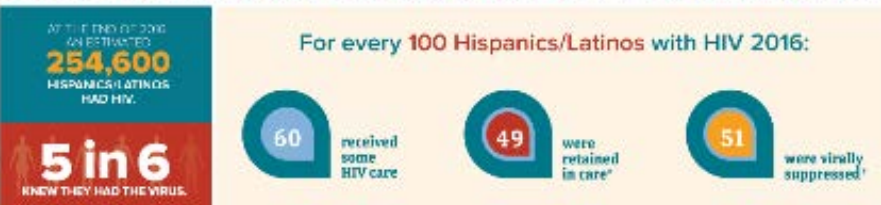
The difference is in the denominators • All people living with HIV (includes persons with diagnosed and undiagnosed infection) is used as the denominator for the prevalence-based continuum. People living with *diagnosed* HIV is the denominator used for the diagnosis-based continuum.



Retention in Care by Demographic



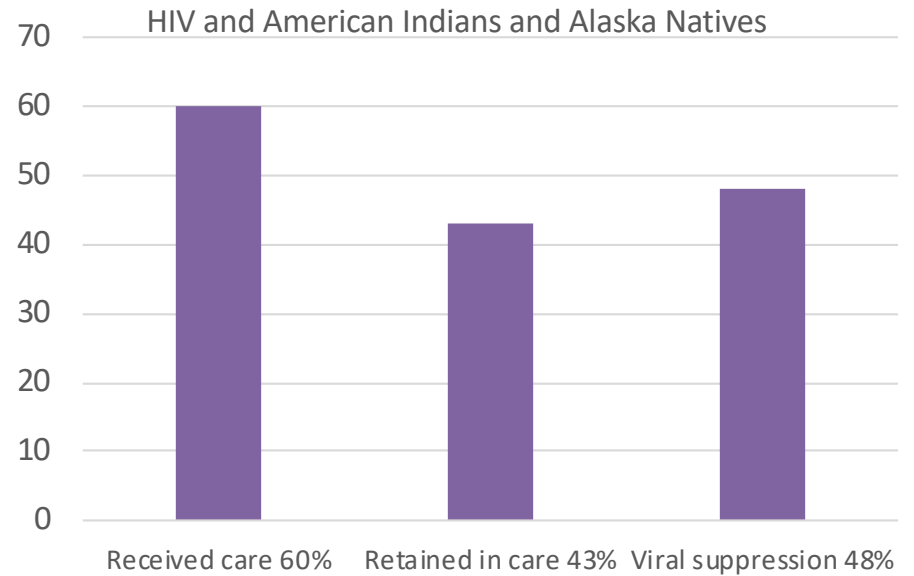
Adult and Adolescent Hispanics/Latinos With HIV in 50 States and the District of Columbia



Asians With HIV in the 50 States and the District of Columbia



Adult and Adolescent Native Hawaiians and Other Pacific Islanders With Diagnosed HIV



Addressing the Root

- Improving retention in care is linked to addressing bias, stigma and racism- it is not always simply solved.
- This can be a long-term process
- Example:
 - ASO in Illinois
 - Low retention in care of Native Hawaiians and Other Pacific Islanders (NHOPI)
 - What do YOU think their next steps should be? Share your opinions in the chat box!

About Cecilia



- Transgender woman
- In recovery
- Formerly incarcerated
- Immigrant
- Formerly undocumented
- Former sex worker
- Ultimate optimist!

Let's Discuss...

What are some reasons you think patients stop showing up?

What are some external reasons patients don't show up?



Depression/Anxiety

Because of depression or anxiety clients have difficulty leaving the house, staying organized, or believing that taking care of themselves is worthwhile.



Health Conditions

Clients struggling with existing (undiagnosed) illness or disabilities may have difficulty maintaining appointments for routine care because of they don't feel well enough to come in.



Competing Priorities

Clients may be struggling to focus on healthcare when other life issues seem more pressing - such as seeking income, housing, or dealing with legal issues.

Other Life Factors...



Affordability

Clients may be having issues maintaining access to affordable healthcare or may be ineligible for insurance making care too expensive.



Transportation Issues

The reliability or cost of public transportation or issues with personal transportation can impede retention in care.



Stigma

Clients may not be ready to accept health conditions such as HIV, Hep C or mental health diagnosis or may be trying to hide those conditions from others.



What are institutional reasons sexual, gender and racial minorities stop coming in for care?

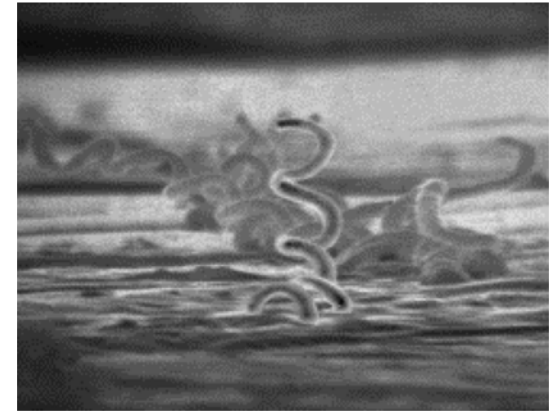
The Historical Basis for Fear of the Medical Establishment



1930's-70's Tuskegee Study - in which 600 black men infected with syphilis were lied to and denied treatment in order to better understand the disease.



Gay/trans conversion therapy - lobotomies, electro-shock therapy and aversive conditioning techniques was common in much of the 20th century and is still legal in many states in the US today.



1940's Guatemala Syphilis Study - in which the US and Guatemalan governments deliberately infected prisoners and mental asylum patients with Syphilis.

Explicit vs. Implicit Bias

You may want to not be a discriminatory person, but unless you address the underlying ideas and beliefs that society has taught you, your behavior may still show a bias against people.

Explicit Bias

Consciously held

Aware of Bias

Deliberate discrimination

Refusing to provide services to a gay person because you have religious objections to their sexuality

Implicit Bias

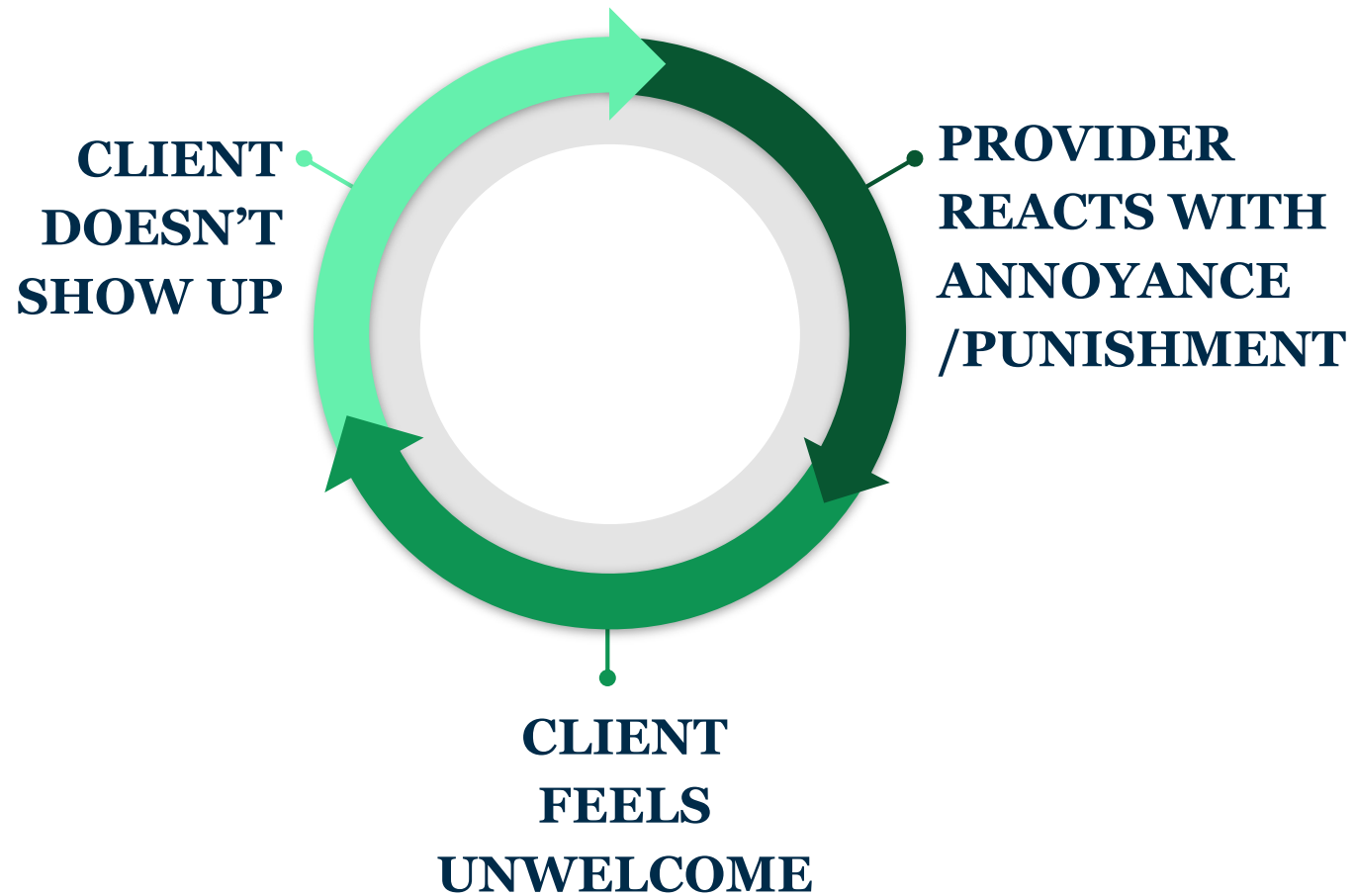
Unconsciously held

Unaware of Bias

Causes indeliberate discrimination

Turning down an immigrant for a job because you feel they'll have a hard time fitting in to the workplace

CYCLE OF DIMINISHING RETENTION



Case Study: Natalia

Natalia is going to a clinic. When she gets there, she asks to use the bathroom and the receptionist, hearing a lower voice, points her to the men's room. When she is filling out the new patient questionnaire, she sees a section that says, "For Women Only:" and a list of questions about menstrual and pregnancy history.

When she meets with the doctor, he asks her why she didn't fill that part of the questionnaire out and she answers that she's transgender. At hearing her say that, he replies that he isn't experienced with transgender care, so he might not be able to treat her. Natalia, frustrated, says that she came in because she's having flu symptoms. Right away he asks her: "So when was the last time you were tested for HIV?"



Credit: Fenway Health

What were the biases at play against Natalia?

What does it feel like when someone has unchecked implicit bias against you?

Feeling pressure to act as a representative for 'your' people

Assumptions that you will behave irresponsibly

Infantilizing advice

Being asked intrusive questions

Being denied treatment or resources

Raised eyebrows or smirks

Being treated in a cold or depersonalizing way

Not being offered services because people don't know how to deal with you

Being engaged with ONLY as your gender, race or sexuality

Uncomfortable facial expressions or body language

What are the consequences of this discrimination?

Low self-worth

A sense of hopelessness in applying for jobs or housing

Feeling like a burden

Internalizing negative stereotypes

Fear around new people

Avoiding seeking medical care even in crisis

Feeling a lack of control over your life

Losing out on opportunity after opportunity

Receiving inappropriate or harmful treatment

Hypervigilance and its effects on your physical and mental health

What do YOU think would improve clients' retention to care?



Retention Without Expectation

A client who only shows up to 1/2 of their appointments still deserves to be celebrated.

Chances are there is something going on that makes coming in difficult, embrace when they are there and create an association with support and recognition rather than annoyance and punishment.



Credit: Gender Spectrum Collection

Harm Reduction Philosophy

“Harm reduction is a set of practical strategies and ideas aimed at reducing negative consequences associated with drug use. Harm Reduction is also a movement for social justice built on a belief in, and respect for, the rights of people who use drugs.”

- Harm Reduction Coalition



What Does Harm Reduction Have to Do with Client Retention?

- Centers clients' goals
- Works with their challenges instead of demanding a lifestyle they're not ready for
- Acknowledges that change is valuable - big and small
- Recognizes that they are the experts of their own lives
- Enables understanding of resistance and the ability to roll with it



Credit: Recovery Research Institute

Rolling with Resistance!

NOTICE IT:

The client interrupts you, seems distracted, gets defensive, goes silent, speaks in negatives: “You can’t help me, you don’t understand.’

RESPECT IT:

You may never understand the source of their resistance, but you can respect that distrust of helping professionals has probably been earned and this is a strategy of self protection

DON’T:

Argue, try to persuade, exert authority, threaten punishment

DO:

Address resistance directly instead of ignoring it, express empathy, ask questions and listen, let go of expert model, be honest

REDUCE IT:

Reflect what we hear without judgement, emphasize personal choice and control, introduce potentially threatening ideas as an experiment

Resistance Activity

How would you respond to these statements in a way that lessens defensiveness and increases trust?

“I don’t have the time to come in for all these appointments.”

“You don’t care about me.”

“I don’t care if I become HIV+”

“If I quit dope, I’ll get sick, so stop trying to make me.”

“I want to get cured, but I just don’t see it happening.”

What Can Managers do to Support Staff in Increasing Retention?



Happier staff = Happier clients!

Do staff have enough sick and vacation days? Do they receive supportive supervision? Are they paid enough to feel valued?



Hire Staff who Relate to the Clients

Having staff who look like and have existing personal knowledge of issues facing clients can profoundly change clients' investment in coming in for care.



Space for Insight over Desensitization

Your staff will need to decompress difficult sessions and should be provided regular opportunities to do that where they can receive support and feedback.

Ongoing and Individualized Training

Not everyone needs the same training! Ongoing skill building and cultural humility should be routine but it's also important to provide opportunities for peoples whose knowledge base might be in a different place than others.



Credit: Create Forward

Is there a training opportunity fund?

Do you have relationships with organizations or individuals that do capacity training, and share those events with staff?

Is there the opportunity for staff to ask for help without feeling like it might result in being punished?



Centering Staff Expertise

Your organization's front-line staff likely know your client population the best and receive the most direct information about what is working or not working for them.

Does your organization incorporate opportunities for direct service staff to provide their input into program development? If managers don't solicit their input, then they are likely ignoring solutions to improve services and increase retention.

Honoring frontline expertise will also create more of a sense of investment in staff, who want to see their suggestions succeed, leading to more care in their work.

Action Item: Consider if your organization is asking the right retention questions!

Do your forms assume clients are cisgender or heterosexual?

Do clients receive reminders about appointments?

Do open hours fit the schedules of your clients?

Are travel stipends available?

Is the reception area welcoming?

Do you address food access? (Provide food bags, hot meals?)

Cecilia Gentili



cecilia@transequityconsulting.com

917-361-0065

www.transequityconsulting.com

Questions?