Health Resources & Services Administration

Session 101: An Overview of HIV-Related Stigma and HIV Care and Treatment in Rural Ryan White HIV/AIDS Program Settings

2020 National Ryan White Conference on HIV Care and Treatment

Tuesday, August 11th, 2020

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HIV/AIDS Bureau (HAB)

Vision: Healthy Communities, Healthy People

Health Resources and Services Administration (HRSA) Overview

- Supports more than 90 programs that provide health care to people who are geographically isolated, economically or medically vulnerable through grants and cooperative agreements to more than 3,000 awardees, including community and faith-based organizations, colleges and universities, hospitals, state, local, and tribal governments, and private entities

- Every year, HRSA programs serve tens of millions of people, including people with HIV/AIDS, pregnant women, mothers and their families, and those otherwise unable to access quality health care

HRSA's HIV/AIDS Bureau (HAB) Vision and Mission

Vision

Optimal HIV/AIDS care and treatment for all.

Mission

Provide leadership and resources to assure access to and retention in high quality, integrated care, and treatment services for vulnerable people with HIV/AIDS and their families.

HRSA's Ryan White HIV/AIDS Program

- Provides comprehensive system of HIV primary medical care, medications, and essential support services for low-income people with HIV
  - More than half of people with diagnosed HIV in the United States – nearly 519,000 people – receive care through the Ryan White HIV/AIDS Program (RWHAP)
- Funds grants to states, cities/counties, and local community based organizations
  - Recipients determine service delivery and funding priorities based on local needs and planning process
- Payor of last resort statutory provision: RWHAP funds may not be used for services if another state or federal payer is available
- 87.1% of Ryan White HIV/AIDS Program clients were virally suppressed in 2018, exceeding national average of 62.7%

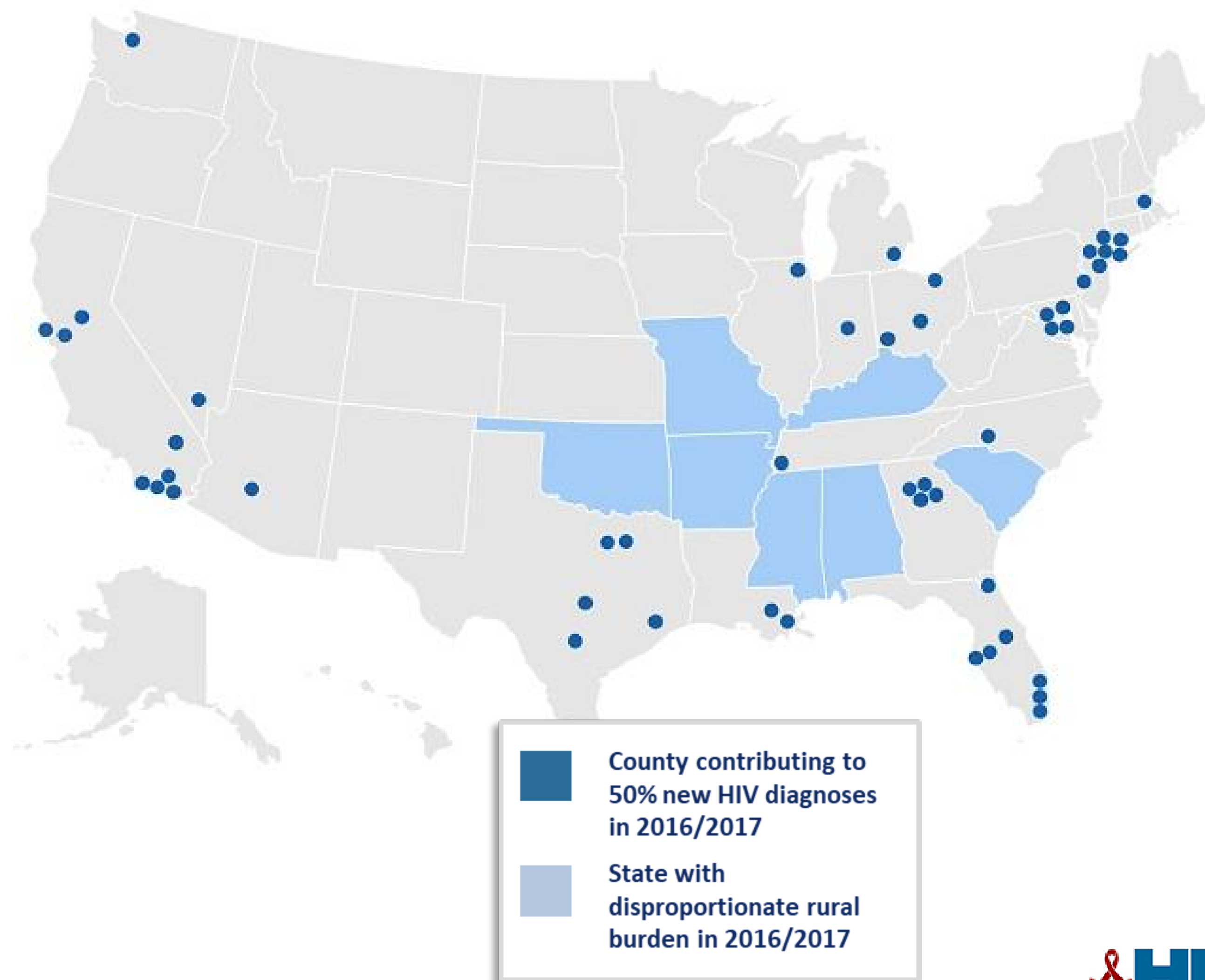
Source: HRSA. Ryan White HIV/AIDS Program Annual Client-Level Data Report 2018; CDC. HIV Surveillance Supplemental Report 2018;21(No. 4)

HAB Rural Health & HIV Workgroup’s Mission

To provide support and resources to HAB recipients and stakeholders to assist in the delivery of optimal care and treatment for people with HIV in rural communities.

Geographic Locations of Ending the HIV Epidemic Initiative

Efforts focused in 48 counties, Washington, DC, and San Juan, PR, where more than 50% of HIV diagnoses occurred in 2016 and 2017, and seven states with substantial rural HIV burden.



HRSA
Ryan White HIV/AIDS Program

Institute Overview

- 101 Session - An Overview of HIV-Related Stigma and HIV Care and Treatment in Rural Ryan White HIV/AIDS Program Settings
  - **Tuesday, August 11, 3:15pm - 4:45pm**
- 201 Session - Federal Resources and Community Initiatives to Reduce HIV-Related Stigma in Rural Areas
  - **Wednesday, August 12, 2:30pm - 4:00pm**
- 301 Session - Innovative Approaches to Reducing HIV-Related Stigma Across Rural Communities
  - **Thursday, August 13, 2:30pm - 4:00pm**

Agenda

I. Overview of the RWHAP in rural communities
II. Introduction to HIV-related stigma
III. Impact of HIV-related stigma on access to health care and HIV clinical outcomes in rural areas
IV. RWHAP Recipient presentation on systemic stigma
V. Question & Answer

Objectives

1. Upon completion of the workshop, participants will learn about HIV health care delivery in rural communities.
2. Upon completion of the workshop, participants will be able to identify the range of stigma people with HIV confront, particularly in rural communities.
3. Upon completion of the workshop, participants will be able to learn from the data and literature of the impact of stigma on rural communities.

Overview of the RWHAP in rural communities

HRSA RWHAP Providers in Rural Areas, 2017

- Nationally, 6.2% of RWHAP providers are located in rural areas
- Approximately 90% of rural providers received Public Health Service Act 330 funding (HRSA-funded Health Centers)
- Nearly half (47%) served 1-99 RWHAP clients

Rural RWHAP Providers (%)
- No Rural Providers
- >0%-9%
- 10%-19%
- ≥20%

Klein PW, Geiger T, Chavis NS, Cohen SM, Ofori AB, et al. (2020) The Health Resources and Services Administration's Ryan White HIV/AIDS Program in rural areas of the United States: Geographic distribution, provider characteristics, and clinical outcomes. PLOS ONE 15(3): e0230121. https://doi.org/10.1371/journal.pone.0230121

RWHAP Funded Services by Rural and Non-Rural RWHAP Providers, 2017

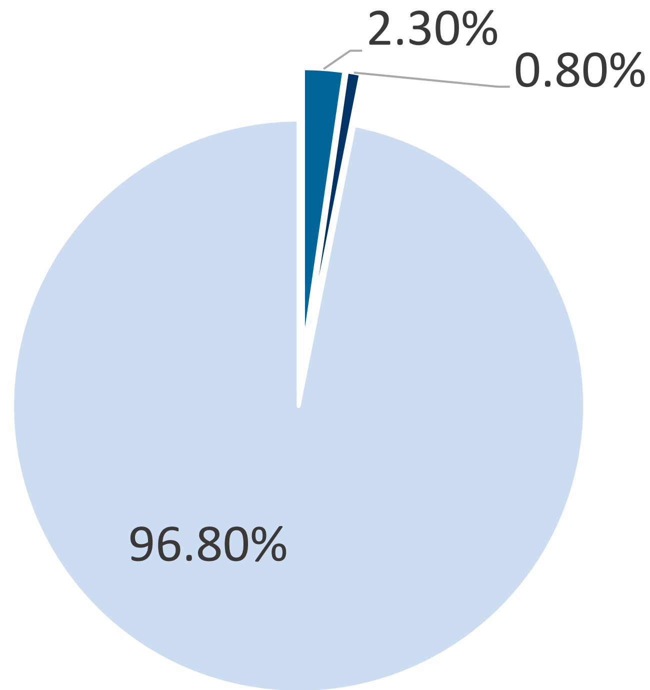
70%
60%
50%
40%
30%
20%
10%
0%

5+ Services
Outpatient Ambulatory Health Services
Early Intervention Services
Emergency Financial Assistance
Food Bank/Home Delivered Meals
Medical Case Management
Medical Transportation
Mental Health Services
Non-Medical Case Management
Oral Health Care
Substance Abuse (Outpatient)

Rural Providers   Non-Rural Providers

Klein PW, Geiger T, Chavis NS, Cohen SM, Ofori AB, et al. (2020) The Health Resources and Services Administration's Ryan White HIV/AIDS Program in rural areas of the United States: Geographic distribution, provider characteristics, and clinical outcomes. PLOS ONE 15(3): e0230121. https://doi.org/10.1371/journal.pone.0230121

RWHAP Clients Visiting Rural and Non-Rural Providers, 2017



- Visited Only Rural Providers
- Visited Rural and Non-Rural Providers
- Visited Only Non-Rural Providers

Clients who visited rural providers (only or in addition to non-rural providers) were more likely to be:

- Older
- White, Non-Hispanic
- Living at or below the Federal Poverty Level
- Uninsured

Klein PW, Geiger T, Chavis NS, Cohen SM, Ofori AB, et al. (2020) The Health Resources and Services Administration's Ryan White HIV/AIDS Program in rural areas of the United States: Geographic distribution, provider characteristics, and clinical outcomes. PLOS ONE 15(3): e0230121. https://doi.org/10.1371/journal.pone.0230121

Retention in Care and Viral Suppression among RWHAP Clients, 2017

	Retained			Virally Suppressed		
	Total No.	No.	%	Total No.	No.	%
Visited Only Rural Providers	**7,536**	**6,246**	**82.9**	**7,855**	**6,718**	**85.5**
Visited Only Non-Rural Providers	330,356	266,937	80.8	344,726	296,132	85.9
Visited Rural and Non-Rural Providers	3,678	2,993	81.4	3,796	3,261	85.9

Retention in care was based on data for people with HIV who had at least 1 outpatient ambulatory health services visit by September 1 of the measurement year, with a second visit at least 90 days after.
Viral suppression was based on data for people with HIV who had at least 1 outpatient ambulatory health services visit during the measurement year and whose most recent viral load test result was <200 copies/mL.

Klein PW, Geiger T, Chavis NS, Cohen SM, Ofori AB, et al. (2020) The Health Resources and Services Administration's Ryan White HIV/AIDS Program in rural areas of the United States: Geographic distribution, provider characteristics, and clinical outcomes. PLOS ONE 15(3): e0230121. https://doi.org/10.1371/journal.pone.0230121

Addressing Needs of People with HIV in Rural Communities

Addressing needs of people with HIV in rural communities means developing **innovative approaches** to, ultimately, retain clients in care and reach viral suppression, including:

- Transportation
- Alternative medical visits (Telemedicine)
- Alternative case management models
- HIV education and awareness (Community Health Workers)

Role of the RWHAP in Addressing HIV in Rural America

- RWHAP providers are a crucial component of HIV care delivery in the rural United States.
- Despite evidence of significant barriers to engagement in care for rural people with HIV, RWHAP clients who visited rural providers were just as likely to be retained in care and virally suppressed as their counterparts who visited non-rural providers.
- The RWHAP, especially in partnership with Rural Health Clinics and the HRSA-funded Community Health Center Program, has the infrastructure and expertise necessary to work towards ending the HIV epidemic in rural America.

Barriers to HIV Care in Rural Communities

Rural communities face barriers to providing HIV treatment and prevention. Some of those barriers to care include:

- Stigma
- Lack of services, specialized service providers
- Transportation to services
- Behavioral substance health conditions
- Staffing
- Lack of HIV education and awareness

Source: Pellowski, J (2013) Barriers to care for rural people living with HIV: A review of domestic research and health care models. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3640620/pdf/nihms406725.pdf

Stigma

Negative feelings, beliefs, and behavior directed toward an individual or group due to a particular label or characteristic.

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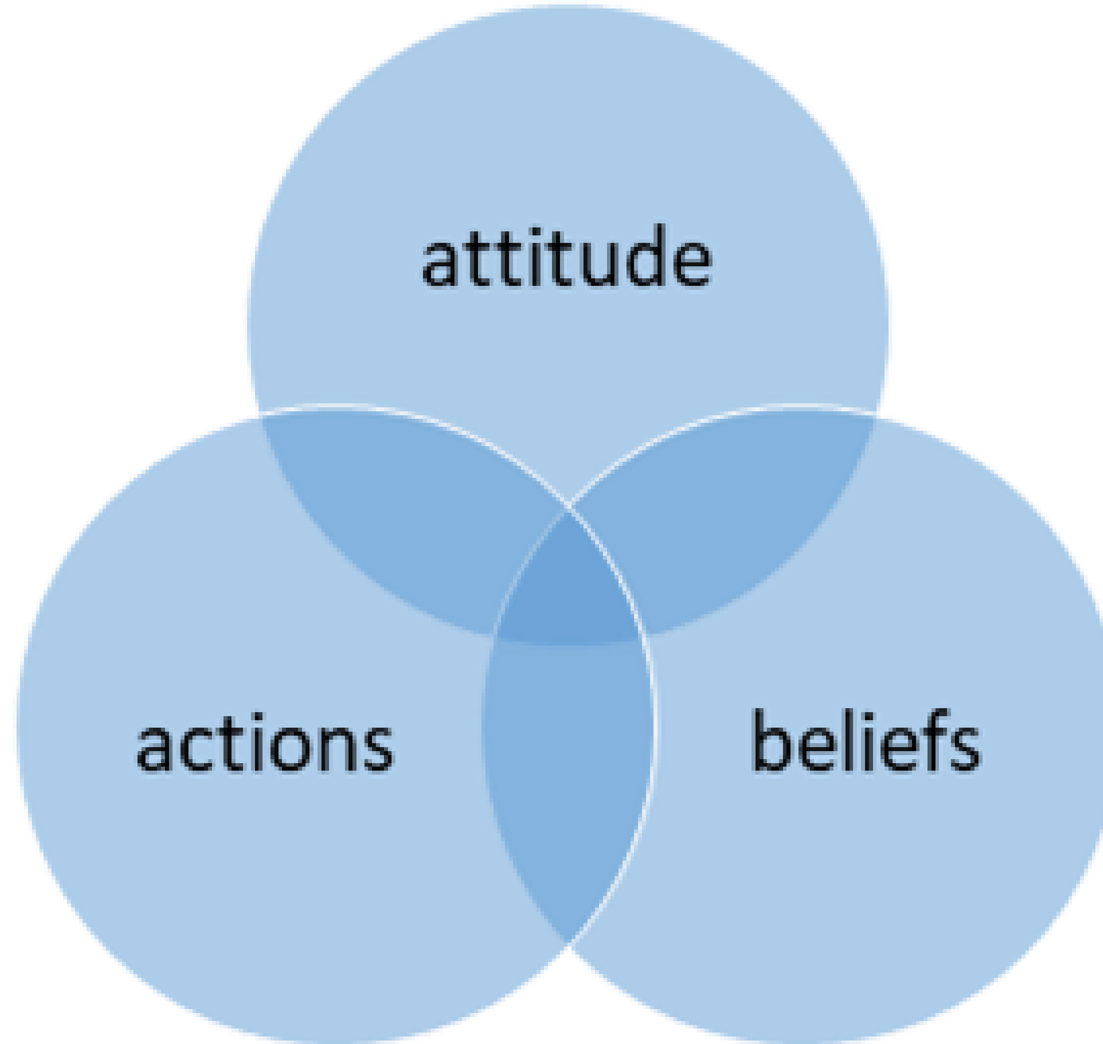
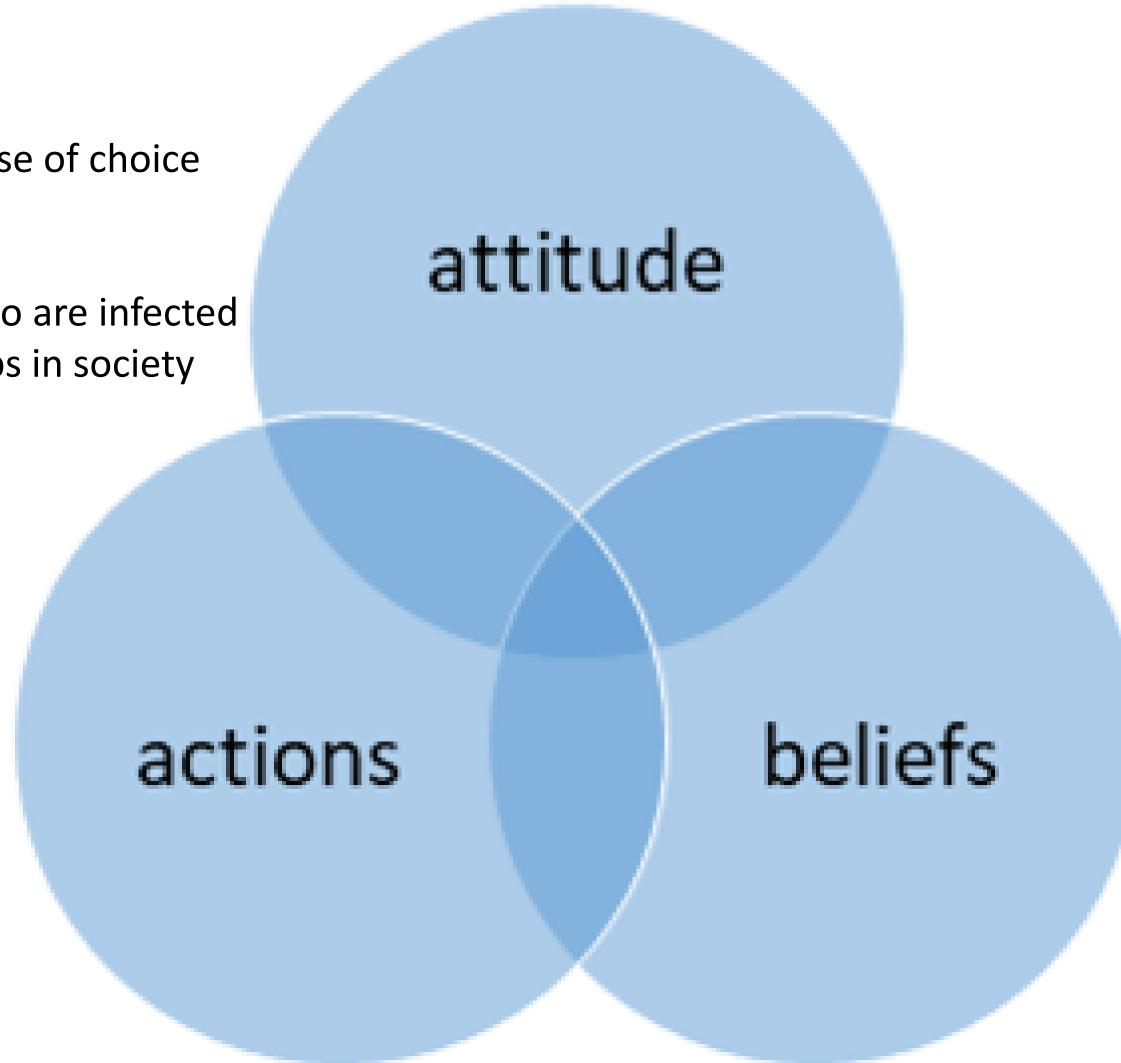
Characteristics of Stigma



Characteristics of Stigma

Attitude:
- Discredit a person or a group
- People deserve to get HIV because of choice
- Fear
- People perceived to be infected
- People associated with those who are infected
- Coupled with marginalized groups in society
- Self-stigmatization - shame



Actions: - unfair treatment
- Discrimination
- Social ostracism
- Refusing contact
- Violating confidentiality
- Diminished support
- Violence

Beliefs:
- Socially unacceptable
- Only certain groups can get HIV
- Stereotypes
- Influenced by myths

HIV Stigma

Primary HIV Stigma

- HIV stigma is manifested through discrimination directed against:
  - Individuals with HIV
  - Groups of people perceived to have HIV

Secondary HIV Stigma

- Individuals, groups, and communities with whom these individuals interact

HIV/AIDS Stigma is manifested through: • individuals with HIV/AIDS, • groups of people perceived to be likely to be infected, and • individuals, groups, and communities with whom these individuals interact. Herek and Capitanio, 1998

Legal Protections for People with HIV

- Numerous federal laws protect people with HIV and AIDS from discrimination
- **Americans with Disabilities Act (ADA)**
  - Guarantees equal opportunities in employment, housing, public accommodations, telecommunications, and transportation, and also applies to all local and state government services https://www.ada.gov/hiv/
- **Fair Housing Act (FHA)**
  - Guaranteed protections from housing discrimination https://www.hud.gov/
- **Affordable Care Act (ACA)**
  - States people with pre-existing health conditions, including HIV, can no longer be dropped from, denied, or charged more for health care coverage https://www.healthcare.gov/coverage/pre-existing-conditions/
- **Health Insurance Portability and Accountability Act of 1996 (HIPAA)**
  - The privacy and security of individuals' medical records and other health information maintained by HHS-funded programs and services is protected https://www.hhs.gov/hipaa/index.html

https://www.hiv.gov/federal-response/federal-activities-agencies/activities-combating-hiv-stigma-and-discrimination

HRSA/HAB Notice of Funding Opportunity on Reducing Stigma

Reducing Stigma at Systems, Organizational, and Individual Client Levels in the Ryan White HIV/AIDS Program

- The purpose of this program is to reduce stigma for people with HIV on multiple levels throughout the health care delivery system, including on an individual client level.
- The program focuses on implementing various stigma-reducing approaches with an emphasis on increasing cultural humility in care and treatment settings for people with HIV within the RWHAP.
- Project period starts September 1st, 2020

Reducing Stigma at Systems, Organizational, and Individual Client Levels in the Ryan White HIV/AIDS Program
To learn more about this funding opportunity: https://www.hrsa.gov/grants/find-funding/hrsa-20-112

Impact of HIV-related stigma on access to health care and HIV clinical outcomes in rural areas

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University of Alabama at Birmingham

2020 National Ryan White Conference (NRWC) on HIV Care and Treatment

Disclosures

- Janet M. Turan has no relevant financial or non-financial interests to disclose.

- This continuing education activity is managed and accredited by AffinityCE in cooperation with HRSA and LRG. AffinityCE, HRSA, and LRG Staff, as well as planners and reviewers, have no relevant financial or non-financial interests to disclose. Conflict of interest, when present, was resolved through peer review of content by a non-conflicting reviewer.

- Commercial support was not received for this activity.

Learning Outcomes

At the conclusion of this activity, participants will be able to:

1. Contrast different types and dimensions of stigma.
2. Explain how HIV-related and intersectional stigma experienced by clients can affect HIV prevention and treatment behaviors, as well as health outcomes.
3. Describe how stigma may be particularly salient in rural areas.
4. Discuss the variety of interventions and tools that can be used in healthcare settings to reduce stigma.

HIV-Related Stigma and Discrimination Persist Globally and Locally

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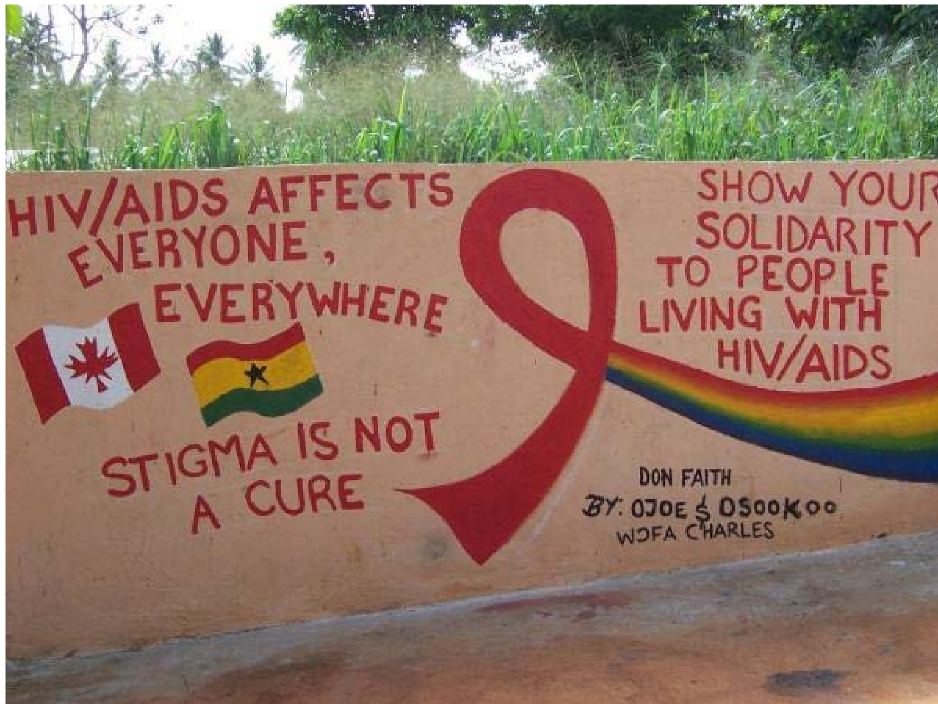
Ghana



Birmingham, AL

* Photo courtesy of Dr. Bronwen Lichtenstein, UA

Dimensions/types of stigma

- Anticipated stigma (fears)
- Normative stigma (perceptions of community norms)
- Experienced or enacted stigma (discrimination)
- Internalized or self stigma

Intersectional Stigma*

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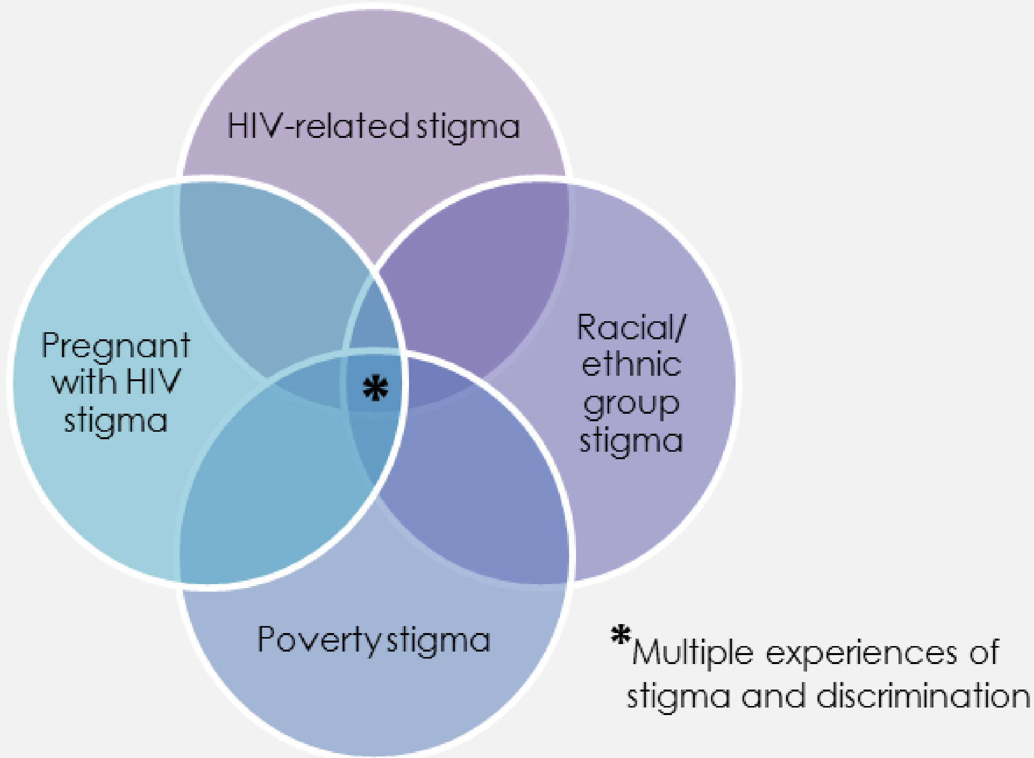
30 YEARS



- These women may experience intersectional stigma because they are:
  - Living with HIV
  - Poor
  - Female
  - In a marginalized racial or ethnic group
  - Being pregnant and living with HIV

* Turan et al. *BMC Medicine*, 2019

How can stigma affect health?

- Stigma adversely affects quality of life and physical and mental health of persons with stigmatized conditions
- Stigma and fears of stigma make people less likely to practice preventive behaviors and/or utilize needed health services
- Stigma can lead to discrimination and violence, with adverse consequences for health

Internalized HIV-Related Stigma Among HIV-Infected Adults in care in the US, 2011–2013*

- From the Medical Monitoring Project (n=13,841)
- Used the Kalichman scale (range 0-6)
- Overall, 79.1% endorsed at least one internalized HIV-related stigma statement.
- The average stigma score was 2.4.
- White males had the lowest stigma scores while Hispanic/Latina females and transgender persons who were multiracial or other race had the highest.

* Baugher et al., AIDS & Behav, 2017

What is known about the effects of HIV-Related Stigma?

Qualitative and mainly cross-sectional studies have found that HIV-related stigma is associated with poor engagement in HIV care and ART adherence*, including:

- Lower acceptance of HIV testing
- Lower access to medical care
- Poorer ART adherence
- Lower utilization of HIV care

*Katz et al., JIAS, 2013; Sweeney and Vanable, AIDS Behav, 2016.

Stigma May Be Common in Rural Areas

- Small close-knit communities (everyone knows everyone's business)
- Less diversity
- Less familiarity with people who are living with HIV
- Social isolation
- Less access to information

Silent Endurance and Profound Loneliness in the Rural South (Miles, et al., Qual Health Research, 2010)

“They don’t want [people with HIV] to come in their house . . . don’t want to touch them . . . don’t want to sit beside them. Hearing comments like that . . . I want to explain to them and tell them what’s going on, but I don’t. I just back down because I think that they’re going to say the same thing about me”.

“They talk about you like a dog. People are just uncaring, insensitive . . . point their fingers and look down on PLWH [like] modern day leprosy.”

“They’re stigmatized because of the fact that they got HIV . . . people look down . . . I guess they figure we’re, how do you say it, degenerates.”

Why Addressing Stigma and Discrimination *in Healthcare Settings* is Important

- Persons affected by HIV may have frequent contact with healthcare providers
- *Fears of stigma, discrimination, and lack of confidentiality in health facilities* can discourage people from:
  - accepting HIV testing / PrEP
  - linking to HIV care after receiving an HIV-positive test result
  - adhering to HIV visits and treatment, or to PrEP
  - Getting other kinds of healthcare that they need

Rebecca's story from the International Conference on Stigma*

- "Once they found out I had HIV, nobody wanted to do my C-section."
- Rebecca's surgery was scheduled at 8 am. At 7 am she got the positive results of her HIV test. But then it was 9 am. And then 11 am. There was no one willing to operate on an HIV-positive patient.
- "And now, every time I go to a hospital or a doctor, I get a panic attack. The feelings of being treated as untouchable come back."

*http://www.whocanyoutell.org/2017-conference/

Stigma in Healthcare Settings

- Fears and experiences of stigma in healthcare settings can both cause internalized stigma and erode trust in healthcare workers, resulting in detrimental effects for the mental and physical health of PLWH.
- Internalized HIV stigma is associated with lower antiretroviral therapy (ART) adherence.
- This association may be stronger for PLWH in racial/ethnic minority groups as compared to whites.

What can we do to reduce stigma in healthcare settings??*

Address immediately actionable drivers

Raise awareness
Discuss and challenge the shame and blame
Address HIV transmission fears and misconceptions

Create partnerships between affected groups and opinion leaders

Contact strategies
Build empathy
Model desirable behaviors
Recognize and reward role models

Affected groups at the center of the response

Develop and strengthen networks
Empower and strengthen capacity
Address self-stigma

*Nyblade et al., JIAS, 2009.

Interventions that address HIV-related and intersectional stigma

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- Interventions that work with health workers
  - Medical/nursing students, current service providers, all levels of staff in a facility
  - In-person workshops, seminars, videos, tablets
  - See Nyblade et al., *BMC Medicine,* 2019.

- Interventions that work with PLWH/community members
  - AA women, Black MSM, Transgender groups, faith-based organizations
  - Group-based and individual interventions
  - See for example Bogart et al. in *Cultur Divers Ethnic Minor Psychol*, 2018

- Interventions that work with both
  - Multi-Country African Study (Uys et al. AIDS Pt Care STDS, 2009)
  - FRESH adaptation for the US (Batey et al. AIDS Pt Care STDs, 2016)

Getting to Zero

0

ZERO NEW HIV INFECTIONS.
ZERO DISCRIMINATION.
ZERO AIDS-RELATED DEATHS.

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Ryan White HIV/AIDS Program Recipient Presentation on Systemic Stigma: Consumer Perspective

Presented by: Gehl Henio

My Heart Story

Story by Gehl Henio

I was born in a body that didn't belong to me…

- I knew around age 6 and 7 that I was a girl inside, but was born a male outside
  - I always felt that I was not normal
  - I did not feel comfortable in my body because being called a boy didn't make sense to me.
  - I was a little girl and didn't know why people didn't see me that way.
- I didn't feel like myself, or that I belonged to my family
  - I was constantly ridiculed and made fun of for my interest in girl things.
- My father always told my mother that I there was something wrong with me for not wanting to play with boys or do things that little boys do.

Growing up in the dark…

- Age 11 to 15 were very difficult and confusing
- I started feeling more uncomfortable in my body during puberty
  - I knew in my soul that I was born a woman, but started to look like a man
- I always wondered why my body did not develop like the other girls
  - I was wearing ladies clothes
  - Growing hair long and styling it
  - I was so confused and disgusted at what was happening to my body

Growing up in the dark, cont.

- I had tried many times to tell my parents that I knew that I was a girl, just to be laughed at, or punished
  - I was living with abuse from both of my parents
  - I learned how to numb the pain by pushing it down and keeping my secrets
- At 14 years old, I ran away to family friends, but was brought back home
  - I told teachers about my abuse at home, but was dismissed after my parents were contacted
  - My abuse increased when they was notified by the school of the abuse

Growing up in the dark, cont.

- At 17, I tried to commit suicide.
  - I was fighting the world everyday. I was feeling all the hatred that I was living. Between the abuse at home and school, I didn't have a safe place to go.
- I was hospitalized, and they would only release me to family.
  - I told the health care workers about the abuse from my father
  - My older sister agreed to take me in

Life with my sister…

- I went to live with my older sister Cher in Las Cruces, New Mexico
  - I was so scared at first because I didn’t know her
  - I was living with a complete stranger

  - I lived with my sister and my niece until I graduated high school
    - I felt so safe
    - I was finally accepted as the lady I am
    - My sister always addressed me as Gehl and made me feel so confident
      - She always used my pronouns SHE/HER
        - I felt myself open up
        - I was able to tell he about my abuse at home

My college experience…

- I started college at the University Of New Mexico
  - I stayed in the co-ed dorms- boys in one hall, girls in the other
  - They had me in single room at the end of the hall
    - I was constantly afraid of being hurt
    - There were many crimes on campus against gay/trans students
      - I was living in limbo
      - I was scared all the time
      - I was scared to be alone at all times
      - I ended up leaving school because of the fear of other students

My battle with addiction…

- At 20, I ended up on the streets of Albuquerque
  - I started drinking
    - I was able to numb pain
    - It gave me the courage to speak up for myself
    - I was beat and sexually assaulted many times on the streets

My battle with addiction, cont.

- I began sex work in Albuquerque to have a safe place to stay and to support my drinking
  - I was sexually assaulted many times
    - I was arrested for prostitution
    - I was verbally abused by the police and called terrible names
    - The more I drank, the more pain I felt

My battle with addiction, cont.

- I began using cocaine and moved to crack
  - It wasn't until I found heroine that I felt that I could finally numb my pain and feel happy and confident again.
  - This went on for 10 years until I developed an abscess in my arm from shooting up
    - It was in the hospital when I was getting surgery, that I was told I was HIV+
      - I had never heard of HIV. I had no idea what it was.
      - I thought I caught HIV because I was so bad, because I was broken
      - Everyone in the hospital stayed away from me and some refused to treat me

My battle with addiction, cont.

- I was sent to Rehab to address my drug addiction
  - I was able to get some counselling
    - I didn’t want to listen, I just wanted to get back out on the streets
    - I couldn’t live without the streets
      - I felt free away from people
        - Away from people that have judged me all my life

        I told the counselors what they wanted to hear to get back to where I felt safe on the streets

My battle with addiction, cont.

- I went back to the streets and continued to use heroin
  - I became a runner for dealers to keep me in money and supply
  - I also continued sex work
    - I didn’t believe my HIV diagnosis
    - I didn’t want to take the medications
    - I did not want to believe that I was sick
  - This went on through my mid 30s

My diagnosis with HIV…

- And then, I got sick- very sick
  - I couldn't breathe
    - The doctors said I had pneumonia caused by AIDS
      - I was in the hospital for five months
      - I knew then that I needed to take control of my life, but I didn't know how to start

My battle with stigma…

- I wanted a fresh start, so I moved to Alaska!
  - I enrolled in UAA for Biology, but the depression around my HIV diagnosis wouldn't leave.
    - I was met with more stigma being a transgender woman
    - Everyone either ignored me, or made fun of me
      - I was bullied, beaten and scared for my life
  - I went back to the streets and back to drugs
    - A lot of people didn't know about HIV
    - No one knew me or my story
    - I didn't know how to get help

Assistance from the RWHAP…

- It took another hospitalization for me to make a change
  - I was referred to the Ryan White Part C Early Intervention Service Department at the Alaska Native Tribal Health Consortium
  - I was also referred to the Ryan White Part B 4A's
    - (Alaska AIDS Assistance Association)

Assistance from the RWHAP, cont.

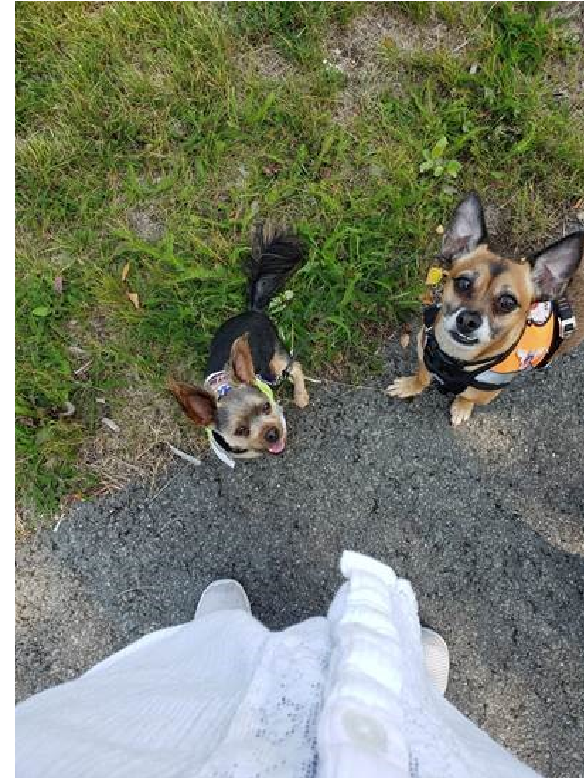
- With support from these services, I have achieved
  - Viral Suppression for 10 years
  - Sobriety for 10 years
  - Stable housing for 8 years
  - Consumer Advisory Board Member for 4 years

My heart story…

- I have become an advocate for HIV treatment and HIV stigma
  - I have had the opportunity to present to my peers and the medical community
  - I have presented my story and my experiences
    - Grand Rounds ANMC
    - Rural Health Summit- Anchorage
    - Circle of Harmony- Albuquerque

My heart story, cont.

- Thank you for letting me share my story



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