Caraconference 2024

Advocacy and Action: HIV Policy as Health Care

September 16–20

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We are Greater Cincinnati's HIV nonprofit devoted to positively changing lives in the fight against HIV/AIDS through:

Prevention

Promoting health and well-being in at-risk communities through evidence-based approaches to prevent disease and reduce the spread of HIV

Housing

Offering a variety of permanent housing support to prevent homelessness and to stabilize individuals living with HIV and their families
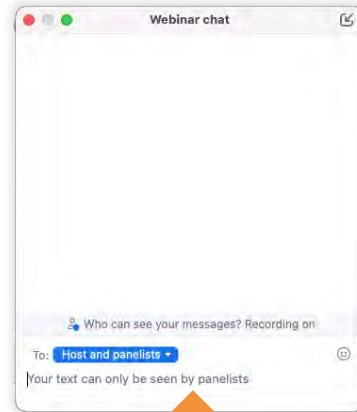
Care

Helping individuals living with HIV access the health care they need through medical case management and pharmacy services
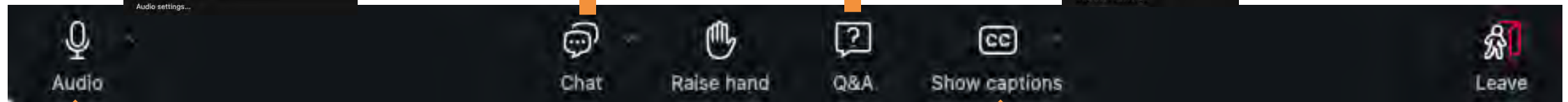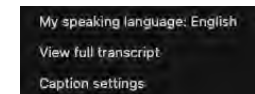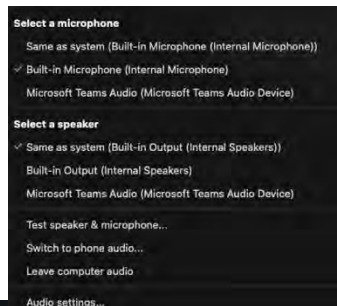
Learn more: caracole.org

How to Use Zoom Webinar

Use Chat to converse with everyone on the webinar and for tech issue questions.

Use Q&A specifically for questions about the content. You may upvote questions from others. You may submit anonymously.
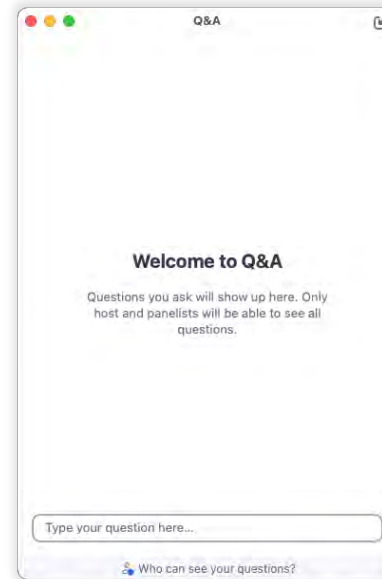
Audio Settings

Caption Settings

Special thanks!

Presenting Partner

Evaluations and Credits

Evaluations recommended for all attendees

Required for CECs

- Link in today's chat and as a post-webinar pop-up

- Must be completed by end of business day (5:00 PM ET) today

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Monday, September 16

Objectives for
Today

1. Identify how HIV stigma negatively impacts HIV prevention and care in various ways.

2. Understand how gender, race, sexual orientation, and socioeconomic status intersect with HIV stigma to impact individual health outcomes.

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Measuring and Challenging HIV Related Stigma: The HIV Stigma Index

Katrina Balovlenkov, LCSW

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Disclosures

- None to report

Mindset: Everyday Stigma

- **Group Discussion**
  - What were some of your experiences with sex education in middle and high school?

  - What early images of HIV do you recall from the mainstream and social media outlets?

Definitions

- **Stigma** - an attribute that links a person to an undesirable stereotype, leading other people to reduce the bearer from a whole and usual person to a tainted, discounted one."*
  - **Internalized Stigma** – Negative views that one holds about themselves as a response to absorbing stigmatizing assumptions and stereotypes from the dominant culture
  - **External stigma** – Also known as social stigma or public stigma is having preconceived notions of negative attitudes, beliefs, and practices originating from the dominant culture

- **Discrimination** – (Othering) the process by which we treat individuals and groups differently, unfairly or poorly because of external stigma; separating ourself from others due to stigmatizing beliefs

- **Discrimination** – (Enacted Stigma) a legal construct within civil rights law that protects "classes" of people in an unequal or unfair manner
  - HIV/AIDS status is protected within this under the umbrella of disability
  - Should it remain classified as a disability?

- **HIV Related Stigma** - HIV and AIDS-related stigma is a complex concept that refers to prejudice, discounting, discrediting and discrimination directed at persons perceived to have AIDS or HIV, as well as their partners, friends, families and communities.

Person First Language

- **Person-first language^ -** a way to emphasize the person and view the disorder, disease, condition, or disability as only one part of the whole person. Describe what the person "has" rather than what the person "is".
  - Person with schizophrenia
- **Identity First Language*** - a linguistic form that links the disability with the person by highlighting their condition or disability first.
  - A schizophrenic

^U.S. Department of Health and Human Services National Institutes of Health. (2024, April 5). *Person-first and destigmatizing language*. NIH Style Guide. https://www.nih.gov/nih-style-guide/person-first-destigmatizing-language

*Surrey County Council (2024, July 22). *Person-first versus identity-first language in additional needs and disabilities support*. Surrey Youth Voice. https://www.surreycc.gov.uk/children/support-and-advice/youth-voice/additional-needs-and-disabilities/person-first-vs-identity-first-language#:~:text=What%20is%20identity%2Dfirst%20language,An%20autistic%20person.

Language Tool

Stigmatizing Terms To Avoid	Use These Alternatives
HIV-infected, HIV-infection*, HIV-positive [people, individuals, populations]	People living with HIV, people with HIV (*see page 8 for comments on use of "HIV-infection")
Subject	Participant, volunteer
Sterilizing cure	HIV elimination, HIV eradication, HIV clearance
AIDS (when referring to the virus, HIV)	HIV, HIV and AIDS when referring to both
Mother-to-child transmission	Perinatal transmission
Verticals	Lifetime survivors
At-risk or high-risk person/population	Person/population with greater likelihood of …, high incidence population, affected community
Target population	Key population/engage or prioritize a population
Hard-to-reach population	Under-resourced, underserved by [specific resource/service], population(s) experiencing discrimination/racism/transphobia

Medical and Public Health Language

- Noting differences between individual healthcare (micro practice) and population level health (macro practice
  - Clinically tailored interventions
  - Clinical guidelines

- Difference between individual level messaging and population health community education
  - Conversations
  - Reported indicators and measures

- Example: Risk

Collaborative Care

Compliance

Adherence
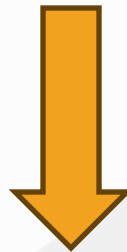
Maintenance

Coping with Stigma

- Responses to Stigmatization:

  - Physically removing the stigma
  - Master the area that stigmatizes them
  - Use their stigma for secondary gain
  - View their stigma as a blessing
  - Reassess the limits of the "normals"
  - Avoid contact with the "normals"
  - Seek out sympathetic others

Goffman, Erving. Stigma; Notes on the Management of Spoiled Identity. Englewood Cliffs, N.J.: Prentice-Hall, 1963

Impact of HIV Related Stigma

Turan, B., Hatcher, A. M., Weiser, S. D., Johnson, M. O., Rice, W. S., & Turan, J. M. (2017). Framing Mechanisms Linking HIV-Related Stigma, Adherence to Treatment, and Health Outcomes. American journal of public health, 107(6), 863–869.
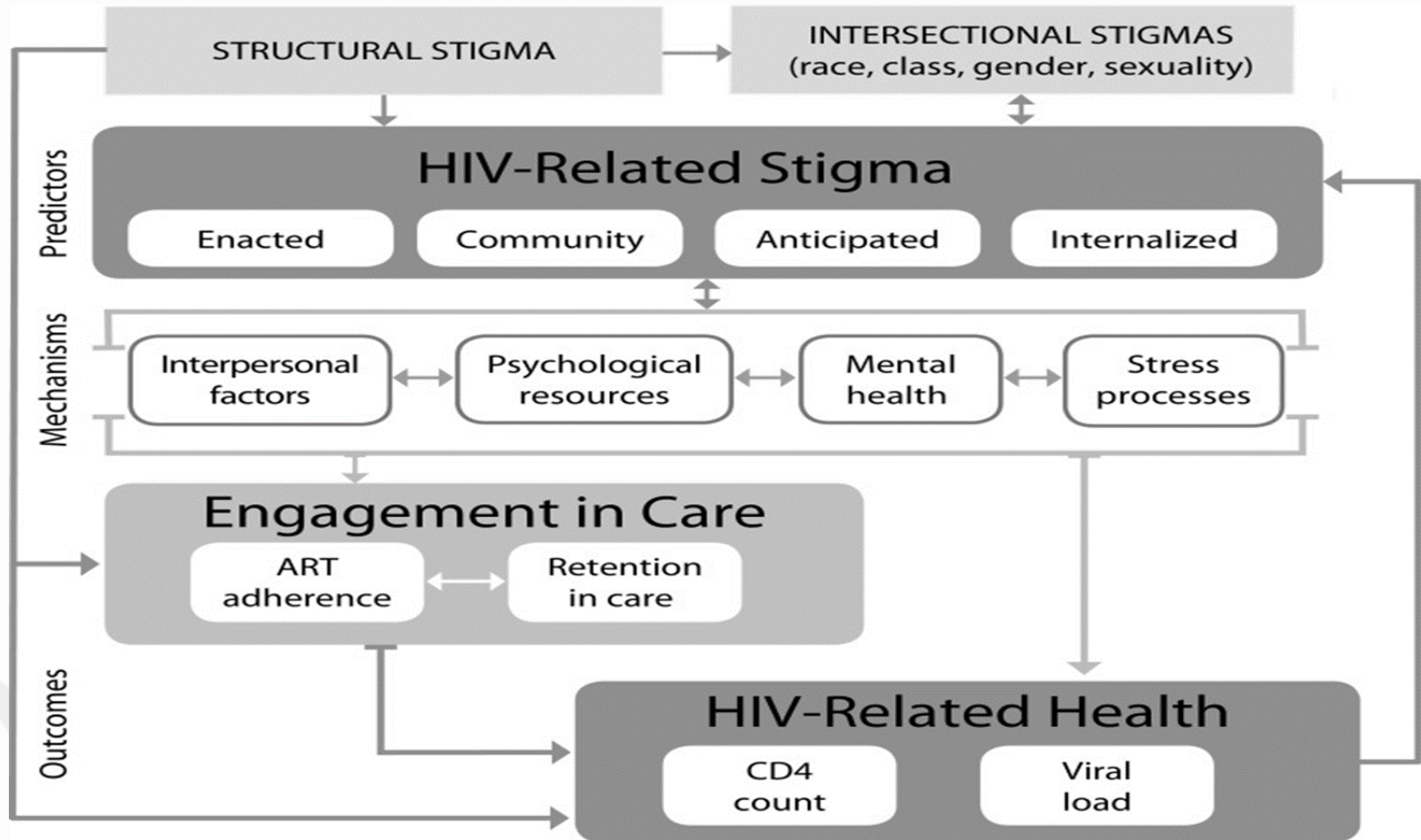
Impact of HIV Related Stigma

- Discrimination can occur at an individual or systems level
  - Discourages testing
  - Discourages engagement in clinical and community based entities
  - Results in social isolation
  - Influences mental health symptoms
  - Creates medical mistrust

Challenges to Measuring HIV Related Stigma

- Current across the US, HIV stigma measurement activities are not uniform and depend on the availability of resources and institutional/jurisdictional buy-in

- There is no one accepted definition for HIV related stigma as it is a subjective measure of the person's own experience

- Respective approaches continue to come out with similar findings that People with HIV continue to experience high levels of stigma and discrimination
  - CDC Medical Monitoring Project
  - GLAAD State of HIV Stigma 2023

Less than **10%** of countries have punitive laws and policies

Less than **10%** experience stigma and discrimination

Less than **10%** experience gender inequality and violence

95% use combination prevention

95% of women access HIV and sexualand reproductive health services

95% of PLHIV know their HIV status

95% coverage of services for eliminating vertical transmission

95% of PLHIV who know their status initiate treatment

95% on treatment are virally suppressed

90% of people living with HIV and people at risk are linked to people-centred and context-specific integrated services

PEOPLE LIVING WITH HIV AND COMMUNITIES AT RISK AT THE CENTRE

Source: UNAIDS (2020), Prevailing against pandemics by putting people at the centre.

PLWH HIV Stigma Index

- "The People Living with HIV Stigma Index is a unique study, as it is conducted by and for people living with HIV, which enhances openness and builds confidence to allow us to share our experiences during the interactions without fear"

- It is a standardized tool to gather evidence on how stigma and discrimination impacts the lives of people living with HIV.

- The intent of this study is two pronged:
  - Data collection
  - Advocacy

HIV Stigma Index Survey

1

Developed by GNP+, ICW, UNAIDS and IPPF, and was first launched in 2008^

2

Completed in over 100 Countries with over 100,000 interviewees

3

Supports the principle of Greater Involvement of PWH*

*GIPA more commonly referred to as Meaningful Involvement by People with AIDS (MIPA) in the US
^Global Network of PLWH, International Community of Women Living with HIV, US Agency for International Development, International Planned Parenthood Foundation

HIV Stigma Index Survey 2.0

- The original survey was updated in 2018
- Domains were added:
  - New questions focusing on specific populations to better understand how different groups of people living with HIV are affected by stigma and discrimination, including key populations.
  - An expanded healthcare section to look at the impact of stigma on health and access to health across the whole continuum of care, not just HIV services.
  - A new questionnaire that is streamlined and easier to use.

- Implementation of a standard methodology was added in 2020

What Do We Know About the Stigma Index Survey

Validation Measures:

- This instrument has been validated for use with diverse populations and reliable for accurate measurement
  - Friedland, Barbara A.a; Gottert, Annb; Hows, Julianc; Baral, Stefan D.d,e; Sprague, Laurelf; Nyblade, Laurag; McClair, Tracy L.b; Anam, Florenceh; Geibel, Scottb; Kentutsi, Stellai; Tamoufe, Ubaldj; Diof, Daoudak; Amenyeiwe, Ugol; Mallouris, Christoforosm; Pulerwitz, Julieb. The People Living with HIV Stigma Index 2.0: generating critical evidence for change worldwide. AIDS 34():p S5-S18, September 1, 2020. | DOI: 10.1097/QAD.0000000000002602

  - Lo Hog Tian, J.M., Watson, J.R., Ibáñez-Carrasco, F. et al. Impact of experienced HIV stigma on health is mediated by internalized stigma and depression: results from the people living with HIV stigma index in Ontario. BMC Public Health 21, 1595 (2021). https://doi.org/10.1186/s12889-021-11596-w

  - Gottert, Anna; McClair, Tracy L.a; Pulerwitz, Juliea; Friedland, Barbara A.b. What shapes resilience among people living with HIV? A multi-country analysis of data from the PLHIV Stigma Index 2.0. AIDS 34():p S19-S31, September 1, 2020. | DOI: 10.1097/QAD.0000000000002587

  - Berger, B.E., Ferrans, C.E. and Lashley, F.R. (2001), Measuring stigma in people with HIV: Psychometric assessment of the HIV stigma scale¶. Res. Nurs. Health, 24: 518-529. https://doi.org/10.1002/nur.10011

AETC Midwest — AIDS Education & Training Center Program

The Principles of the PLHIV Stigma Survey

The guiding principles of the PLHIV Stigma Index are:

Capacity building
The lead network is expected to guide the entire implementation process, but it is not left to do this on its own. It is encouraged to work in collaboration with partners in country (such as research institutes) and technical assistance is available at every step of the way from the International Partnership.

Accountability and ownership
The Stigma Index centres around the GIPA principle, the Greater Involvement of People Living with HIV/AIDS. People living with HIV are not only the interviewers and the participants, but the entire research design and implementation process is led by and for people living with HIV. Local network(s) of people living with HIV decide for themselves if they would like to conduct a Stigma Index in their country and the experiences and knowledge of people living with HIV are at the centre of the whole process.

Embracing equality and diversity
Whichever network takes the lead, all those involved in the implementation process should pro-actively work to ensure gender equality and to embrace the diversity that exists among the whole community of people living with HIV, including key populations living with HIV (gay men and other men who have sex with men, transgender people, sex workers, and people who use drugs).

Advocacy-oriented
The data that is gathered through the Stigma Index enables a clear picture of stigma and discrimination to emerge. It also provides evidence for advocacy to shape policy and programmatic change and end HIV- related stigma and discrimination.
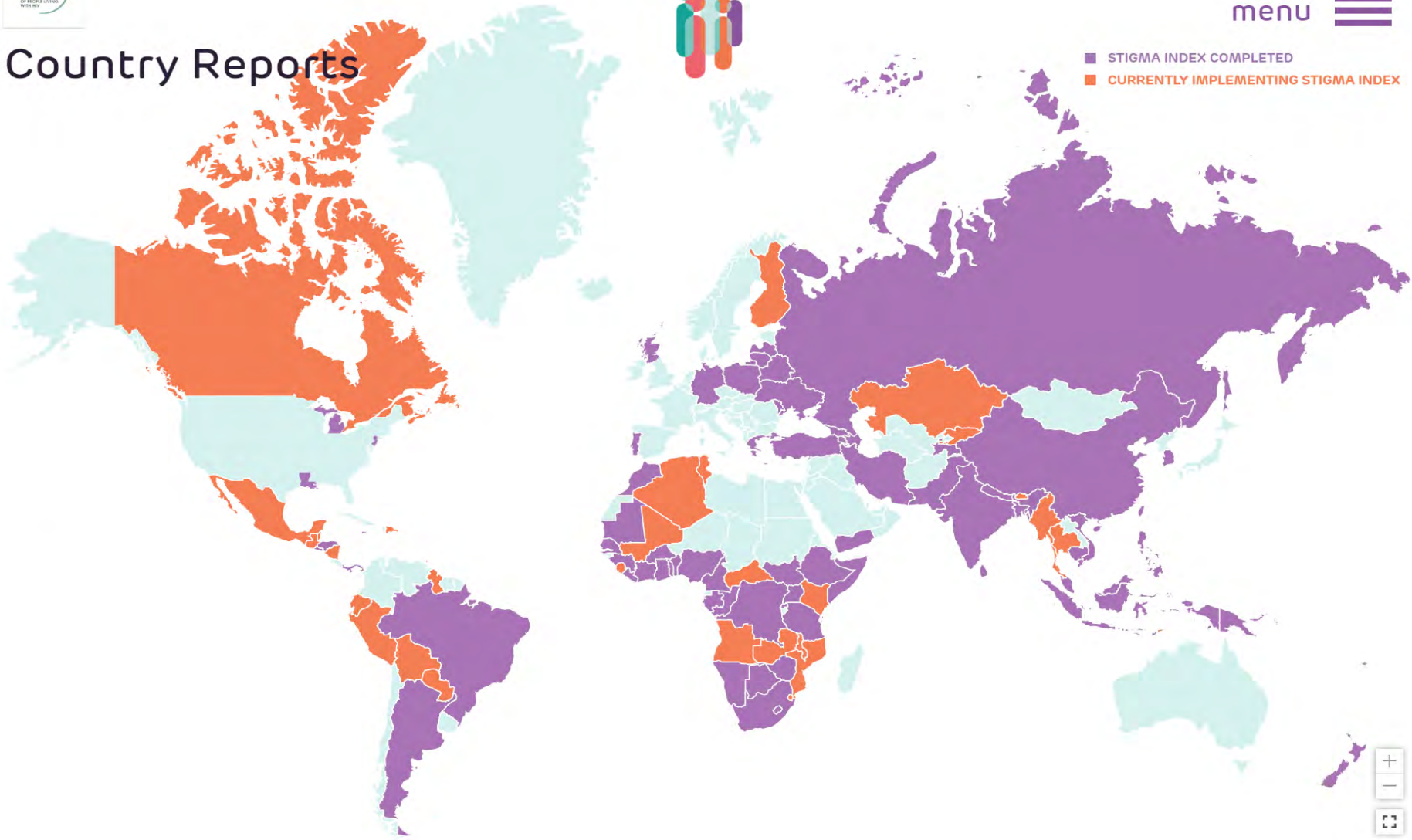
Where the Work is Being Done

Country Reports

menu

STIGMA INDEX COMPLETED
CURRENTLY IMPLEMENTING STIGMA INDEX

AETC Midwest
AIDS Education & Training Center Program

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Implementation:
How do we study stigma in the community?

Active Implementation Framework

Duda, M.A., Jaouich, A., Wereley, T.W., Hone, M.J.G. (2019). How to Apply Implementation Science Frameworks to Support and Sustain Change. In: Pollastri, A., Ablon, J., Hone, M. (eds) Collaborative Problem Solving. Current Clinical Psychiatry. Springer, Cham. https://doi.org/10.1007/978-3-030-12630-8_3

Principles of Implementation Science:
Closing the Know-Do Gap

Competency Drivers:

- What resources and trainings are needed to get the job done?
- Which personnel and how many do we need to get the job done?
- What challenges do we anticipate moving forward in our work?

Organizational Drivers, Barriers, and Facilitators

- What strengths and tools will help us to overcome obstacles and reach our goal?
- Will data collection be paper or electronic?

Leadership Drivers:

- Who are the "champions" in this project?
- How do we lead with community (is it organization leading or PWH?)
- How do we achieve community buy-in from suppressed, depressed, and oppressed people living with HIV?

AETC Midwest
AIDS Education & Training Center Program

Implementing the PLWH HIV Stigma Index

Ready! Set! Go!

To start this process, there is a two-page Intake Form that must be completed and submitted to the International Partnership

✓ The PLHIV Stigma Index is a continuous and systematic **journey of activism** to address HIV-related stigma and discrimination

Global Network of People Living with HIV. (2022b, September 23). *Your journey.* People Living with HIV Stigma Index. https://www.stigma
index.org/journey/

Maintenance

Maintaining

- Maintenance is not a static process
  - The findings from the report should continue to shape policies, programs, and processes within the context of your respective environment or on a larger advocacy stage
  - Resulting interventions must include the community as the center of transformation
  - Documents must be living and breathing to rapidly respond to changes in the epidemic and the impact to those must vulnerable

Examples
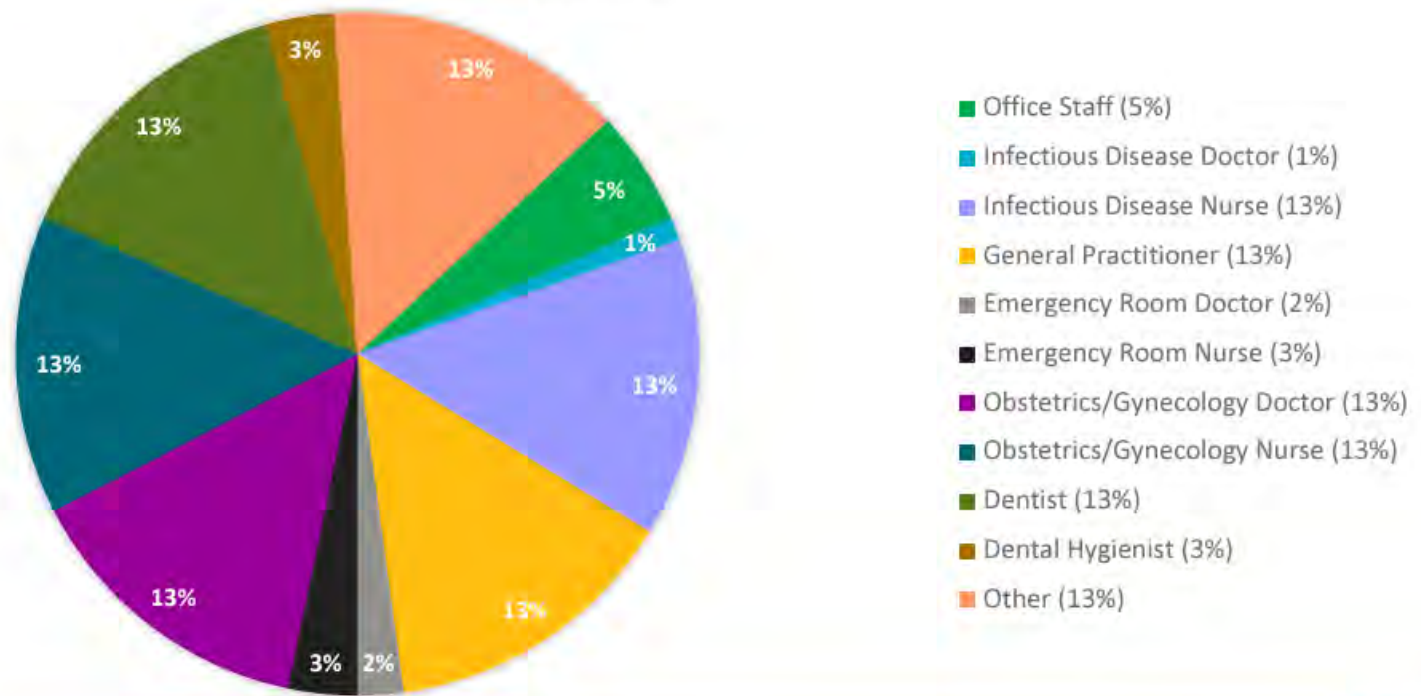

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Louisiana

The PLHIV Stigma Index 2.0 is currently underway in Louisiana, led by Positive Women's Network USA (PWN-USA).The PLHIV Stigma Index has been previously implemented in New Orleans and Baton Rouge in 2017.

Results The Louisiana Stigma Index Project:

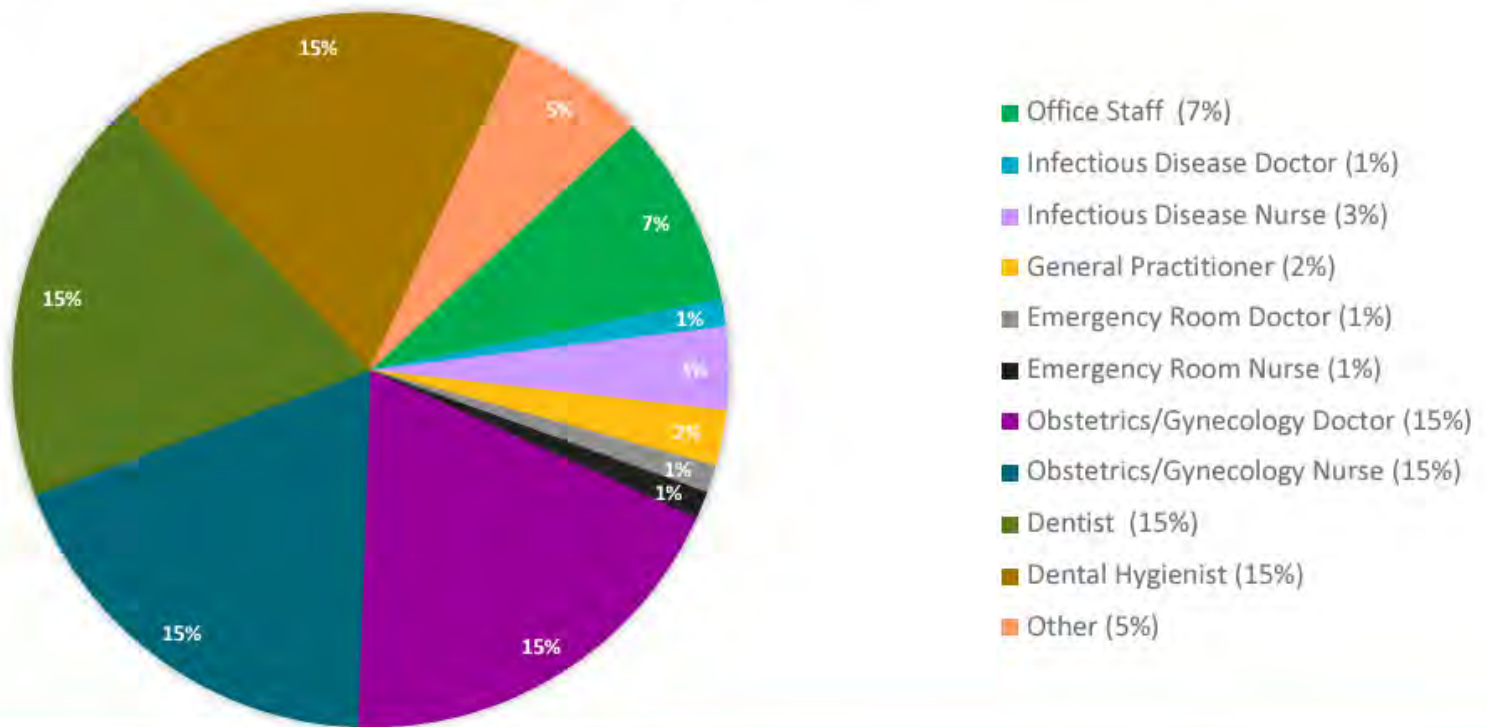Data Results: **Stigma** (Baton Rouge)

HEALTHCARE WORKERS THAT DISCRIMINATED AGAINST PARTICIPANTS IN LAST 12 MONTHS

- Office Staff (5%)
- Infectious Disease Doctor (1%)
- Infectious Disease Nurse (13%)
- General Practitioner (13%)
- Emergency Room Doctor (2%)
- Emergency Room Nurse (3%)
- Obstetrics/Gynecology Doctor (13%)
- Obstetrics/Gynecology Nurse (13%)
- Dentist (13%)
- Dental Hygienist (3%)
- Other (13%)

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Results: Continued

Data Results: **Stigma** (New Orleans)

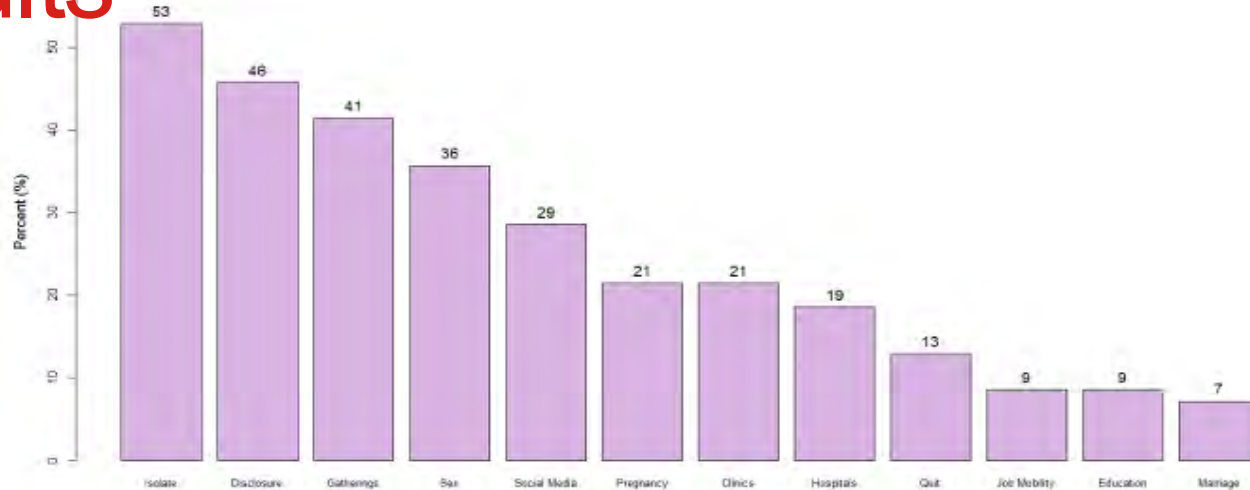HEALTHCARE WORKERS THAT DISCRIMINATED AGAINST PARTICIPANTS IN LAST 12 MONTHS

- Office Staff (7%)
- Infectious Disease Doctor (1%)
- Infectious Disease Nurse (3%)
- General Practitioner (2%)
- Emergency Room Doctor (1%)
- Emergency Room Nurse (1%)
- Obstetrics/Gynecology Doctor (15%)
- Obstetrics/Gynecology Nurse (15%)
- Dentist (15%)
- Dental Hygienist (15%)
- Other (5%)

Michigan

Results

Figure 20. Engagement in Social Avoidance Behaviors

|	
Isolate	I have isolated myself from my family and/or friends
Disclosure	I decided not to share my HIV status with someone who might have provided support to me
Gatherings	I have chosen not to attend social gathering(s)
Sex	I decided not to have sex
Social Media	I decided not to participate in social media (Facebook, Twitter, or other) because I was afraid that my HIV status might be found out
Pregnancy	I decided not to have (more) children
Clinics	I avoided going to a local clinic or doctor when I needed to
Hospitals	I avoided going to a hospital when I needed to
Quit	I made the decision to stop working
Job Mobility	I decided not to apply for a job/work or for a promotion
Education	I withdrew from education/training or did not take an opportunity for education/ training

Results
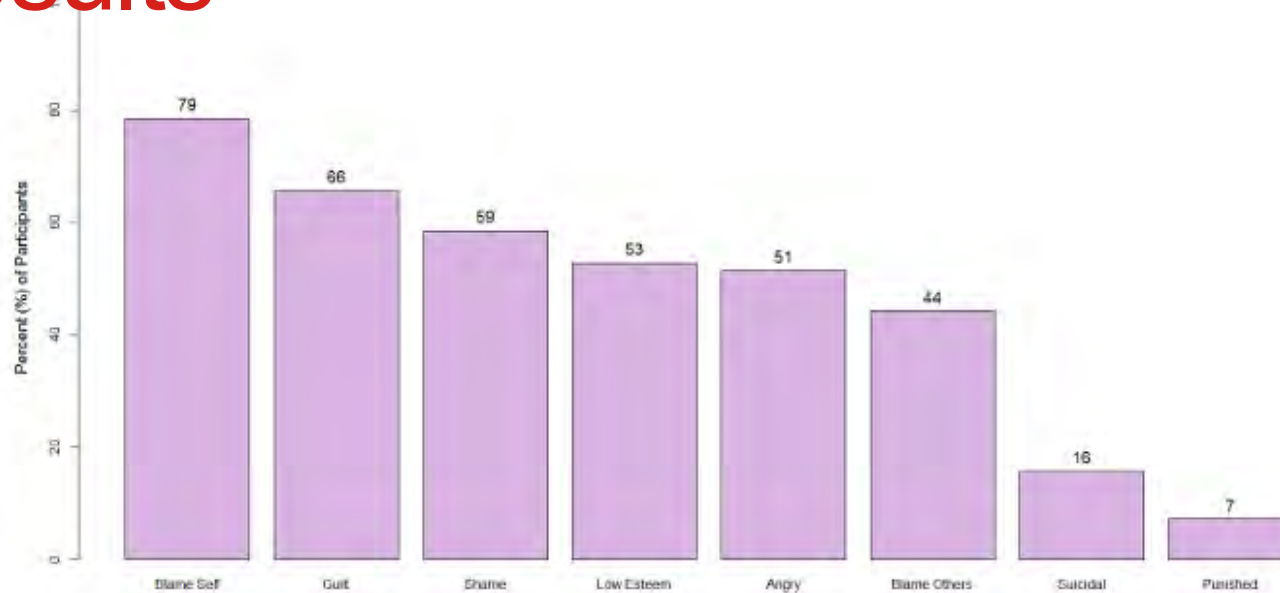
Figure 16. Percent of Participants Reporting Negative Feelings about HIV Status in the Prior 12 Months

Blame Self	I blame myself
Guilt	I feel guilty
Shame	I feel ashamed
Low Esteem	I have low self-esteem
Angry	I feel angry
Blame Others	I blame others
Suicidal	I feel suicidal
Punished	I feel I should be punished

Next Steps: QUALITATIVE RESEARCH TOOLKIT:

A guide to support networks of people living with HIV in conducting qualitative research for the People Living with HIV Stigma Index

https://www.stigmaindex.org/wp-content/uploads/2022/03/PLHIV-Stigma-Index-Qualitative-Toolkit_WEB_EN.pdf

WHAT QUESTIONS DO YOU HAVE?

MATEC Resources

- National Clinician Consultation Center http://nccc.ucsf.edu/
  - HIV Management
  - Perinatal HIV
  - HIV PrEP
  - HIV PEP line
  - HCV Management
  - Substance Use Management

- AETC National HIV Curriculum https://aidsetc.org/nhc

- AETC National HIV-HCV Curriculum https://aidsetc.org/hivhcv

- National PrEP Curriculum https://www.hivprep.uw.edu

- Hepatitis B Online https://www.hepatitisb.uw.edu

- Hepatitis C Online https://www.hepatitisc.uw.edu

- AETC National Coordinating Resource Center https://aidsetc.org/

- Additional Trainings https://matec.info

Duda, M.A., Jaouich, A., Wereley, T.W., Hone, M.J.G. (2019). How to Apply Implementation Science Frameworks to Support and Sustain Change. In: Pollastri, A., Ablon, J., Hone, M. (eds) Collaborative Problem Solving. Current Clinical Psychiatry. Springer, Cham. https://doi.org/10.1007/978-3-030-12630-8_3

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HIV Language Guide (NIH Publication No . 24-AI-7480)

The Louisiana Stigma Index Project: Results and Next Steps (14 March 2017). https://www.stigmaindex.org/wp-content/uploads/2022/06/USA-SI-Presentation-Louisiana-2017.pdf

Lo Hog Tian, J.M., Watson, J.R., Ibáñez-Carrasco, F. et al. Impact of experienced HIV stigma on health is mediated by internalized stigma and depression: results from the people living with HIV stigma index in Ontario. BMC Public Health 21, 1595 (2021). https://doi.org/10.1186/s12889-021-11596-w

Surrey County Council (2024, July 22). Person-first versus identity-first language in additional needs and disabilities support. Surrey Youth Voice. https://www.surreycc.gov.uk/children/support-and-advice/youth-voice/additional-needs-and-disabilities/person-first-vs-identity-first-language#:~:text=What%20is%20identity%2Dfirst%20language,An%20autistic%20person

U.S. Department of Health and Human Services National Institutes of Health. (2024, April 5). Person-first and destigmatizing language. NIH Style Guide. https://www.nih.gov/nih-style-guide/person-first-destigmatizing-language