

**Caraconference 2024**

**Advocacy and Action:  
HIV Policy as Health Care**

**September 16–20**





**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

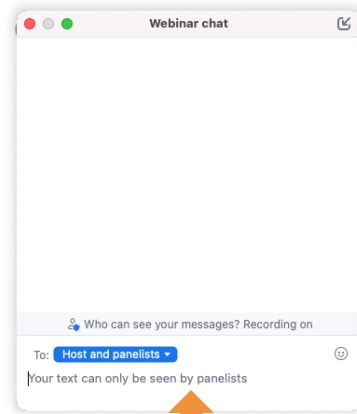
## **Care**

Helping individuals living with HIV access the health care they need through medical case management and pharmacy services

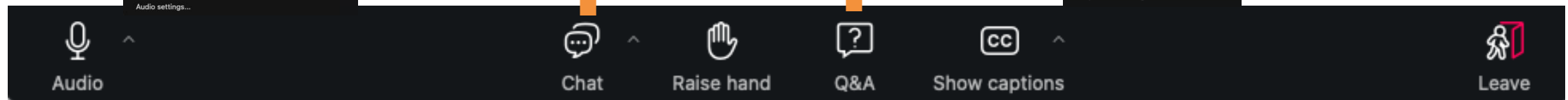
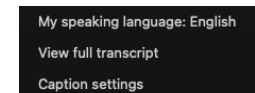
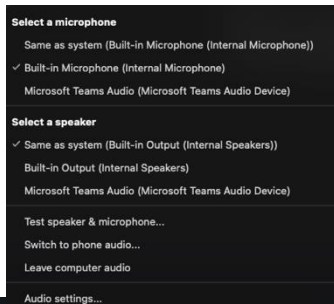
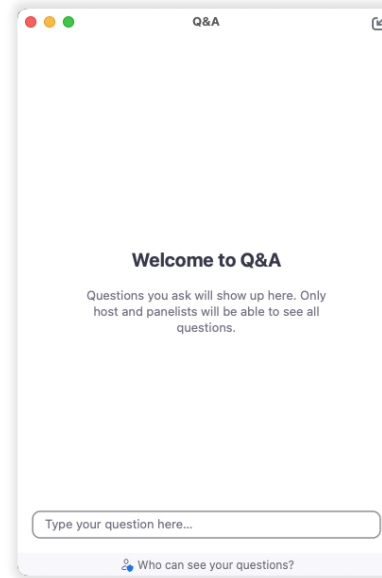
**Learn more: [caracole.org](http://caracole.org)**

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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.



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**Special thanks!**

**Presenting Partner**

**matec**  
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# 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

**Caraconference 2024**  
**Friday, September 20**

# **Self-Advocacy to Action**

Presenters: Zoey Peach, Adam Reilly and Ariel Shaw



Friday, September 20

# Objectives for Today

1. Describe three types of advocacy/advocates
2. Understand how social determinants of health impact one's ability to self-advocate
3. Identify legal rights and recourses for people living with HIV
4. Explore effective strategies for advocating to lawmakers and public policy officials



# Self-Advocacy to Action

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Zoey Peach, Ariel Shaw and Adam Reilly

September 20, 2024



# Agenda for **Today**

Self-Advocacy Types and History

Self-Advocacy in Medical Settings

Know Your Rights

Action: Policy and Advocacy

# Types of Advocacy/Advocates

- Self-Advocacy: the ability to understand and effectively communicate one's needs to other individuals without compromising the dignity of oneself or others.
- Peer Advocacy: taking action to represent the rights and interests of someone other than yourself.
- Group Advocacy: taking action to influence social, political, and economic systems to bring about change for groups of people.
  - Awareness Events
  - Lobbying

# Self-Advocacy: A Brief History

- Self-advocacy is rooted in the disability rights movement, specifically among people with intellectual and developmental disabilities
- Self-advocacy contrasted with caretaker-led models
- In healthcare, self-advocacy is rooted in the early days of the AIDS epidemic and in the concept of cancer survivorship

# How Who You Are Impacts Advocacy

## Race and Ethnicity

One study found that there is evidence of lessened self-advocacy among racial and ethnic minorities in healthcare settings. This can be attributed to multiple factors, such as:

- Differences in role expectations
- Disengagement due to feeling stereotyped
- Lack of opportunities to participate
- Mistrust of medical system

## Spoken Language

When individuals do not speak the same language as their healthcare provider it can be difficult to advocate for oneself. One study found that among patients who did not speak the local language:

- 49% had trouble understanding a medical situation
- 66.7% faced a barrier when accessing healthcare
- 20% did not seek healthcare services if these were not readily available for fear of not understanding their healthcare provider

# Self-Advocacy in **Medical Settings**

# Advocacy in Healthcare

## Structural Barriers

- Gender: 33% of trans people who saw a healthcare provider in the past year reported having at least one negative experience related to being trans.
- Geography: The federal government projects a shortage of over 20,000 primary care physicians in rural areas by 2025.
- Race and Ethnicity: It has been found that Black and Latino people receive lower-quality care compared with White people, even after insurance coverage and income have been adjusted for.

# Advocacy in Healthcare

1. Identify what you want and need from your appointment and communicate with your physician.
2. Come prepared. Before your appointment, do your research about your treatment and/or your condition
3. Keep a copy of your medical records, treatment, and progress for your own reference.
4. Don't be afraid to get a second opinion.
5. Reach out to those around you and build your support system.

# Know Your Rights



## KNOW YOUR RIGHTS

# Your Bill of Rights as a Patient

- You have the right to the respectful care
- You have the right to request information concerning your healthcare
- You have the right to discuss and request information regarding procedures and treatment
- You have the right to know the identity of providers who are providing you care
- You have the right to be notified of the finances associated with your care and treatment
- You have the right to make decisions regarding your plan of care and treatment
- You have the right to a power of attorney (someone who can make decision on your behalf)
- You have the right to privacy
- You have the right to privacy and confidentiality regarding your healthcare information
- You have the right to review your records regarding your healthcare
- You have the right to request a transfer of care, evaluation of care, referral(s), etc.
- You have the right to inquire about any business relationships between the hospital, healthcare providers, healthcare entities that could influence treatment and care.
- You have the right to consent or decline participation in research studies/or human experimentation
- You have the right to reasonable continuity of care
- You have the right to be informed of any hospital related policy and procedures regarding your care.

## **What exactly is the law in Ohio?**

OH Rev. Code § 2903.11: Felonious Assault: If you know you are HIV positive and engage in “sexual conduct” without disclosing your status, it is a 2<sup>nd</sup> degree felony (2-8 years)

OH Rev. Code §§ 2907.24 and 2907.25: Prostitution or solicitation while living with HIV is a 3<sup>rd</sup> degree felony (9-36 months)

OH Rev. Code § 2907.241 Loitering to engage in solicitation while living with HIV a 5<sup>th</sup> degree felony (6-12 months)

OH Rev. Code § 2921.38: Harassment with a bodily substance: causing another person to come into contact with blood, semen, urine, feces, or other bodily substances is 3<sup>rd</sup> degree felony for people living with HIV (9-36 months)

OH Rev. Code § 2927.13: Donation: Selling or donating blood, plasma, or blood products is a 4<sup>th</sup> degree felony for PLHIV (6-18 months)

# HIV Criminalization 101

- In the state of Ohio, Ohioans can be charged with second degree felonious assault and placed in prison if they fail to disclose their HIV status to sexual partners.
  - If convicted under the felonious assault law of not disclosing HIV status to a sexual partner, one is required to register as a sex offender.
- In addition, PLWHIV can have their status used against them at the hands of abusive partners. (EX – if you leave then I'll tell the police you knowingly attempted to give me HIV.)
- Penalties for PLWHIV can be 2 to 29 times longer than those who do not have HIV, and potential fines can grow up to 3 times.

## KNOW YOUR RIGHTS

# Law Enforcement

- You are only required to provide law enforcement officers with your name, address, and date of birth.
  - Maintain a record of all interactions with law enforcement.
  - You are allowed to request name, badge number, etc from the police officer.
- You have the right to an attorney
- You do not have to provide your HIV status and are NOT required to consent to any medical testing (blood draws, saliva swabs, etc.)

## KNOW YOUR RIGHTS

# Workplace

- You do not have to disclose your HIV status. They cannot ask if you are living with HIV while interviewing or before making a job offer.
- You cannot be fired from a place of employment due to your HIV status.
- An employer can ask medical questions when:
  - Engaging in affirmative action for people with disabilities
  - You ask for a reasonable accommodation.
  - Once a job offer is made, prior to employment, and everyone entering the same job category is asked the same questions.
- During employment if there is evidence you may be unable to perform duties or pose a safety risk due to your condition.
- Contact Equal Employment Opportunity Commission (EEOC) if you believe your rights have been violated. EEOC can assist in your next course of action and investigate if you decide to file a charge of discrimination.

## KNOW YOUR RIGHTS

# Persons Living with HIV

- According to the rehabilitation act of 1973, the Americans with disabilities act of 1990 and the affordable care act, PLWHIV are protected from discrimination based on their HIV status
- If you feel that you have been discriminated against due to your status, you have the right to file a complaint with the US department of Health and Human Services Office for Civil Rights

Action:  
**Policy and Advocacy**

# Reactionary VS. Proactive

- Why is it hard to engage the larger community in advocating for policy change?
  - Normalcy bias—Human tendency to not account for changing conditions in the future
  - Delay discounting—Idea of taking less now rather than waiting on a bigger “pay out” later
  - Diclinism—Unmotivating belief that the future is dark compared to a rosy past
  - Individual level VS. Community level—The idea that societal problems are caused by individual choices, not community level choices. False view.



# Engaging with the future

- To advocate for true policy change one must connect today's actions with tomorrow's consequences
- Notable example: In 2003 the field of Early Childhood Development adopted the "*Active Metaphorical Language of Building Brains*"
- Goals is to reduce childhood poverty, abuse, neglect, and increase housing stability through highlighting the long-term value of positive relationships, supports, and experiences during the earliest years of life
- In some communities the adoption of this model has led to lower rates of poverty, abuse, and neglect while seeing some increase in housing stability. It is thought that wide adoption of this model will have a greater impact. However, many barriers exist in various states and jurisdictions.

# Engaging with the future

- The model adopted in the Early Childhood Development field is a good example of “Legacy Thinking”
- Legacy Thinking is the desire to have a positive impact on future generations—this must be harnessed to have effective policy change
- When advocating for change one must emphasize solutions just as much as the problem
- Many issues policy change is looking to correct are very large and daunting for people. Being solutions based and focused will help to alleviate people’s apathy around such large issues

# Engaging with the future

- One must remain factual, share data, and other supporting documentation to convey your status as a subject matter expert on given topic
- Cannot fully rely on numbers/data/stats as it is hard for people in power or not to connect those numbers with real people's experiences
- Such information is most powerful when directly connected to a person and their experiences related to specific policy change one is advocating for. Personal experiences coupled with factual information and solutions-oriented approach will get the best reception
- When advocating for policy change context must be given as well. How does this policy change intersect with other existing policies and how does this change impact people's day-to-day life