

Hard Topics Discussion

How can we expand opportunities and decrease barriers so communities of color, women, and transfolk are more involved in the HIV care and prevention processes or systems that are in place to reduce HIV in Minnesota?

Tuesday, July 19, 2022
10:00 – 10:45 a.m.
Microsoft Teams

Attendees:	
Shea Amaro	Teresa Jones
Joe Amrhein	Océane Lune
Danielle Brantley	James McMurray
Belinda Charleston-Green	Jim Mitulski
Megan Higdon	Lesla Nelson
Julian Hines	Jay Orne (facilitation)
Annalise Jackson	Sarah Schiele (facilitation)
Stephen Jensen	Gage Urvina
MCHACP Staff:	
Carissa Weisdorf, Coordinator	Bryan Bick, Administrative Specialist (minutes)

I. Introduction

- Sarah Schiele and Jay Orne introduced themselves. They are members of the Minnesota Council for HIV/AIDS Care and Prevention and serve on the council's Disparities Elimination Committee.
- Sarah explained that they will be using a focused conversation facilitation method to structure the conversation. This method leads participants through a series of questions: objective (what?), reflective (gut), interpretive (so what?), and decisional (now what?).
- Sarah stated that the goal of the conversation is to identify or create ways that the council can facilitate more opportunities for marginalized communities to be involved in the HIV care and prevention processes and with the council, and to identify and mitigate barriers for people of marginalized communities to be involved.
- Sarah and Jay shared data from the Minnesota Department of Health's 2021 HIV Statistics.

II. "What?" question: What stood out to you in the data that was presented?

- Sarah shared that the breakdown of new HIV diagnoses in 2021 by race and ethnicity compared to the overall population in Minnesota by race and ethnicity stands out to her.
- A participant agreed that the numbers of new HIV diagnoses in 2021 seem to be the inverse of the total population in the state when examined by race and ethnicity. It reminded them of the service prioritization exercise the council just did. The disparities

by race and ethnicity seemed like a problem to address above all else, starting with who has access to health care and who does not.

- A participant who is also on the council wondered why it has been a struggle to have more non-white members join and participate.
- A participant shared that they are not surprised by the data because these disparities in HIV diagnoses by race and ethnicity have been constant for decades. They mentioned that historical trauma in the medical field plays a large role in why people of color are reluctant to participate in the council. They stated that the HIV services systems are failing the community, especially Black people, Latinx people, and people of color generally.
- Another participant who is on the council shared that he did not know it existed until his case worker recommended it. He stated he is still trying to understand the language of what the council does and that it is hard to trust the medical community to even get basic health care needs met. He felt the makeup of the council is not reflective of the community it serves, and sometimes people on the council feel like they must be the voice of their communities.
- A participant who is also on the Disparities Elimination Committee (DEC) stated there was no data from the state on the transgender population until a few years ago. DEC fought for representation of transgender and non-binary individuals in the data. Because people don't see their experiences reflected in the data or at the council, the council decided to hold a position for a transgender or gender non-conforming individual. They concluded that the council could make changes if it wants, and it just has to be persistent.
- A participant expressed concern that heterosexual cisgender men have few services dedicated to them, and they don't always feel comfortable in the support groups that are available.

III. "Gut" questions: What parts remind you of your own experience with barriers? What makes you feel heard by the council? When have you felt heard by the council?

- A participant shared they are Black and Latinx and were diagnosed with HIV at age 15. They felt they had privilege in their introduction to HIV services because they met their case manager early on, they have stable housing, and they can remain adherent to HIV medications. They said co-occurring factors like homelessness or barriers to accessing gender-affirming care while transitioning need to be addressed. They said these conversations have been happening for 10 years, but things have not changed. They asked what we can do to change the data, instead of just looking at the data.
- A participant said they were diagnosed in early 2020, and it was hard to find help because we were in the early stages of the pandemic. They didn't know about the African American AIDS Task Force, they were homeless, and they tried different medical providers before finding a good fit.

IV. "So what" question: Who is missing from this discussion, and who should we make sure to keep in mind as we move forward into thinking about next steps?

- A participant said presenters at council and community meetings often don't allow for questions until the end, and the information is covered too quickly. People don't understand the information and disengage from the conversation.
- The meeting participants agreed that the transgender community is missing from conversations about planning for HIV services and prevention.
- A participant felt that input from the community was missing and suggested using the council Facebook page to get more information out and to gather more feedback.
- A community member shared that people who are both consumers and providers of HIV services are often overlooked. They pointed out that government agencies and AIDS service organizations encourage involvement from people with lived experience but forget about them once they take positions of leadership.
- A participant expressed frustration with coming to meetings that are just focused on data. They said the community already knows the statistics and wants follow-through. Once the data is collected and studied, what is going to be done about it, and how will agencies be held accountable?

V. "Now what" questions: What are some actionable steps to address the issues? What do you think are most important ways for more people to be involved? *(The group was divided into breakout rooms to discuss, and then brought back to the larger group to share their top action idea.)*

- A participant said her breakout group talked about visibility. She never sees advertising materials for the council at places like Rainbow Health and Aliveness Project, even though materials are supposedly shared there. The community can't know about the council or its committees when they are not advertised, and it feels like the council is a secret.
- Another participant in the same breakout group said visibility has been an issue for years. She tries to be intentional about sharing events that are going on in the community. It can be challenging because people aren't seeking out the information. Also, medical appointments for HIV care are becoming less frequent, so people aren't seeing going into clinics as often to see the information. HIV information, including Undetectable=Untransmittable, should be everywhere, with QR codes that people can quickly scan so they have it on their phones to look at later.
- A participant stated that HIV feels very private in the Duluth area, and we do not really know who is being impacted by HIV there. He proposed having a town hall conversation on HIV with different community groups in Duluth. It could be done on a weekend with food to encourage people to come.
- A participant said it is important to have qualitative data in addition to quantitative data because people are more responsive to stories.
- A participant mentioned that the council relies a lot on partnering with different organizations, but it should take more action independently as the council and represent itself as a separate entity.
- A participant said his top priority was getting more people on to the council who represent disproportionately impacted communities. He mentioned that the council

allocates a large amount of money, and by being on the council you can have a voice and a vote.

- A participant recommending devoting more time to these hard topics conversations. They also suggested that the council could hire a consultant to work with the council to see how it is doing at meeting the goals of this discussion.

VI. Thank you and closing: Sarah and Jay thanked the participants for taking the time to join the meeting and promised to keep the conversation going.

BB/cw