

# Community Involvement Activities Committee

## MEETING SUMMARY

*The Planning Council believes that the voice of the community is paramount. The purpose of the CIAs is to help bridge the gap between the community and service providers by creating opportunities to involve community members in the planning process. In addition, community members will receive crucial updates on changes in the Ryan White and related health/social services.*

**Wednesday, January 26, 2022 from 5:16 PM to 7:08 PM**  
 Video-Conference via Zoom: <https://zoom.us/j/96635953539>  
 Teleconference: (929) 205-6099 / Meeting ID: 966 3595 3539#

**Attendees:** There were 16 attendees at the meeting and participated in the Zoom call.

Attendees by County							
Essex	Union	Morris	Sussex	Warren	Unknown	Other	Total
12	3	1	0	0	0	0	16

**Support Staff:** Tania Guaman and Unnati Guru

**1. Welcome and Moment of Silence**

Warren Poole, Committee Chair, called the meeting to order at 5:16 PM and welcomed all in attendance. A moment of silence was observed for all those living with, those who have passed, and those affected by HIV/AIDS. Poole provided a brief overview of the CIA’s purpose and goals.

**2. Public Testimony**

One attendee shared the following information:

Two pieces of legislation were passed by the state, signed by Governor Murphy as part of a harm reduction package:

- One took away a town rule regarding syringe access programs and gave it back to the Department of Health, so that the DOH can make determinations based on epidemiology as syringe-sharing for IV drug use is one mode of HIV transmission.
- The other bill will be repealing the criminalization laws in the State of New Jersey. In 1991, there were non-disclosure laws when Ryan White was first introduced which were not based on science.

As part of this harm reduction package the governor signed, people that were prosecuted for having syringes can have it expunged, and there will be a task force put together to monitor overdose in New Jersey.

**3. Approval of the Meeting Summary from November 17, 2021**

The November 17<sup>th</sup> meeting summary was sent electronically for review prior to the meeting. Poole asked for a motion to approve the meeting summary as presented. One attendee motioned and another seconded. No abstentions or oppositions.

The December 15<sup>th</sup> meeting summary was also reviewed during the meeting as it was a short paragraph regarding the Holiday Social events that attendees participated in. Poole asked for a motion to approve the meeting summary as presented. One attendee motioned and another seconded. No abstentions or oppositions.

#### **4. Ryan White Part A Updates**

Guaman provided the following update:

- HRSA released a new program letter: Gender Affirming Care in the Ryan White HIV/AIDS Program. This letter emphasizes the importance of gender-affirming care as it effectively addresses the health and medical needs of transgender people with HIV. Gender affirmation describes processes whereby a person receives social recognition, value, and support for their gender identity and expression.
- Attendees discussed what they believed gender-affirmation meant, and Guru provided a brief overview of what gender-affirming care would look like, providing the following examples: using one's preferred pronouns, providing varying gender identities on intake forms, medical professionals and staff taking cultural sensitivity and inclusive care training, and showing acceptance and support of one's identify that may not align with cultural gender norms practiced in America.
- Some questions and concerns brought up involved how one would know which pronouns to use when addressing an individual and when it would be appropriate. One attendee also noted some webinars involve attendees noting their preferred pronouns at the end of their name or introduction, but that it is not common practice in person.
  - One suggestion to combat these concerns was identifying a respectful way in which one asks an individual their preferred pronouns upon introduction, such as "Would you mind sharing your preferred pronouns?" This is one way to normalize a variety of gender expressions, whether in or outside of gender norms, and make it a practice to not assume gender identity based on a person's physical presentation.
- The committee came to the agreement that a big part of gender-affirming care and gender affirmation is respect.

#### **5. Old Business**

##### **Planning for the 2022 – 2026 Integrated HIV Prevention and Care Plan**

- Continued conversations about Community Engagement
  - Attendees discussed methods of engagement and outreach for youth ages 18-34 and transgender identifying individuals. Suggestions include:
    - Using flyers, which can be shared and distributed amongst schools and colleges; pride and LGBT centers; guidance counselors; events both within and outside of Newark; and providers, who can share them with clients.
      - Flyers should have contact info so youths can speak to someone for more information to ensure privacy and discretion
    - Outreach to healthcare settings that particularly serve the LGBT+ population such as AIDS Healthcare Foundation

- Inviting people from, or sharing about the PC at, gay and/or lesbian bars or Pride/LGBT+ rallies
- Making connections with social workers at schools or centers, as they may be open to hosting an event where people can learn more about the Planning Council and ask questions, either in public or privately to the speakers/hosts
- Connecting with Non-Ryan White Providers, such as Infectious Disease doctors and providing flyers to them about the PC to get the word out to clients
- Outreach to other areas outside of Newark as the Covid-19 epidemic is overshadowing the HIV epidemic
  - One attendee noted deaths being identified as due to Covid from having tested positive could instead be due to pre-existing symptoms or conditions in someone living with HIV, which may or may not have been exacerbated by Covid: “So many people have died from Covid, and because of the cloud of Covid, when someone passes away from HIV/AIDS related problems, the first thing they want to tabulate it as they passed away from Covid, because they may have tested positive for it. They don’t look at the fact that it may have been something that is related to the problem they already had at hand, which was HIV and AIDS.”

## 6. New Business

### Discuss barriers and needs to end the HIV epidemic: Diagnose, Treat, Prevent, Respond

- Attendees discussed barriers and needs consumers experience from the moment they get tested to getting into prevention care or treatment. Barriers and needs identified include the following:
  - Youths lack care for their health, including sexual health, until it leads to a drastic change in lifestyle, such as a hospital visit or health issue. “They have a lot of information they’ve gained in the past couple of decades, they don’t think about viral load and T-cells until something drastically happens to them. They may use protection after finding out, but until they end up in the hospital, they’re not really doing to concern themselves with any kind of programming until push comes to shove and they need it.”
  - The Covid-19 pandemic is a barrier, as it is causing other health issues to be pushed to the wayside.
    - Funding sources for other health conditions, such as HIV, heart disease, diabetes, and cancer, are also being shifted towards Covid-19 prevention and care, such as vaccines and pop-up clinics. “People forget that before Covid, you know, we had this virus coming around and that was just as bad as cancer. It’s really taken away from the financial status of helping people with HIV and AIDS. The push for more funding for Covid research and spending money on vaccines and we are still dealing with this nonsense and it’s not fair to people with cancer, with diabetes, heart disease.”
    - “Covid right now is one of the biggest barriers to people getting diagnosed or linked to care or anything, because it’s become the primary concern of everything going on right now. It’s like HIV was pushed way back, maybe not even on the stove anymore. People have forgotten about it.”

- Youth face different challenges than those who are older, as they are busy with work, school, and family. They need a way to receive information that also allows for privacy.
- One attendee shared the following experience of lack of information regarding HIV/AIDS: There was a heterosexual man, in a relationship with his wife for twelve years. The wife knew the attendee because they are an activist who is upfront about who they are, and state their HIV is a part of who they are. The husband had tested positive for HIV and was diagnosed with AIDS. A question the wife had was if HIV remain dormant for twelve years. She believed she was in a monogamous relationship with her husband and thought he got HIV prior to their relationship. The couple still believed it was a gay disease, and the husband had not gotten tested, even though he showed physical symptoms.
  - The attendee questioned whether the husband was properly linked to care once he received the diagnosis or if he was told about different AIDS service organization and programs that may be available to him. These questions were brought up because the husband had met with the attendee after his diagnosis and mentioned he was concerned about his whether his insurance company would cover his HIV medications because they were expensive. The attendee connected the husband with an AIDS service organization, but this experience brought up the following questions:
    - What information did the husband receive upon his diagnosis?
    - Was the husband not able to retain all the information or was it simply never provided?
    - What is being done on the provider side when an individual receives a traumatic diagnosis to ensure the consumer knows there is help out there for them?
- One of the biggest barriers noted was stigma:
  - One attendee noted: “As a nation, we need to stop the stigma. As a nation that started the problem by blaming it on gay men. I was diagnosed with an incurable problem, and when they came out with this gay disease that they call it, I myself, knowing that I was terminal, said I don’t want to get *that* disease. People are not only getting the diagnosis that they might die, they are getting a diagnosis as if they are terrible people, that they did something wrong.” This needs to be controlled and managed. The same effort put into creating the stigma needs to be put in to remove the stigma and normalize HIV.
  - Another added that people feel shame and embarrassment for being HIV positive or having people know about their HIV status, such as if someone from the community saw them walking in or out of a clinic. The attendee mentions that resources are available, but people need to be willing to go out and obtain the resources.
- Lack of proper sexual health education such as safe-sex practices and emphasis on its importance, especially for young people, as they feel it would not happen to them.
- Fear of using existing resources or going to organizations that provide comprehensive care such as appointments to meet the doctor and resources to pay for medication and medical bills. “He may have been embarrassed or didn’t want people to know about his diagnosis, so he just never went for help. They don’t want anyone in their community to know, so they just don’t do anything and continue on with their life. Resources are out there, it’s just that people have to get up and go to the resource. The resources aren’t going to come to them.”

- Linkage to care may not always be provided outside of HIV testing sites or HIV clinics, as one attendee mentioned they were tested for HIV at a hospital emergency room twelve years ago. The attendee stated “They just told me my diagnosis and they sent me home. I had to find out everything on my own. There was absolutely nothing, they didn’t even have a doctor or an office or a phone number. I was fortunate I had people in my circle that were familiar and helped me to navigate my way through the system. I found a clinic, that I could go to, and a good doctor, and other agencies that were helpful, but there was absolutely no connection when I was diagnosed. This was over twelve years ago, but still I believe that’s what the situation may still be.”
- One must choose to be linked to care.
- Covid-19 is a barrier to spreading knowledge about HIV: HIV was being brought up on TV commercials, but due to the pandemic, Covid-19 ads have taken over.
- One attendee shared that trust between sexual partners is also a barrier, as they tested positive after having relations with the opposite sex who was an injection drug user: “It comes down to the trust factor. They trusted the person they slept with, and that person broke the trust. It was someone that I trusted, not knowing that he was an intravenous user, not knowing that he already knew he had the virus. I got sick and got pneumonia, and that is how I found it. They didn’t treat it as a big deal [the medical professional]. Not knowing about follow up, this is where you can go. Things are more wide open now. It became a trust issue: I can’t trust this person; they may be a drug user or might have the virus.”
  - The attendee clarified this lack of trust for partners due to this experience did not extend to providers
- Testing clinics should keep promoting safe sex practices as those who go to clinics for HIV/STI testing are still testing positive for other STIs, which raises the question: Are these individuals having issues accessing condoms, or is it a lack of knowledge/practice?

### **Review the Newark EMA preliminary goals for 2022-2026**

- Attendees took turns discussing what they believed would help end the HIV epidemic and what goals they felt needed to be achieved to do so. Suggestions included:
  - Talking more about U=U and status neutral: be there for people who test negative by providing preventative care and sexual health education
  - Bringing the focus to HIV through the use of commercials and ads, identifying people as being an actual patient, HIV positive, and for how long to spread the word that the medications work, and HIV is not a death sentence.
  - Breaking the stigma around HIV by stressing the fact that HIV is an epidemic, it is everyone’s disease, and everyone needs to stand together
  - Providing proper sexual health education: HIV prevention medication does not prevent all STDs/STIs
  - Pop-up HIV/STD/STI testing sites, like COVID pop-up sites, which provide education and referrals
  - Providing free care for HIV, just like with COVID as both mess with the economy; giving people what they need to prevent HIV and suppress their viral loads
  - Finding a cure for HIV/AIDS

**7. Announcements**

- February 7 is National Black AIDS Awareness Day - This was started as a grassroots education effort to raise awareness about HIV and AIDS prevention, care, and treatment in communities of color.

**8. Next meeting**

The next CIA meeting will be held on Wednesday, February 23, 2022, at 5 PM via Zoom to continue the Integrated Planning.

**9. Adjournment**

The meeting was adjourned at 7:04pm.