

Community Involvement Activities MEETING SUMMARY

Wednesday, November 20, 2019, at 5PM-7PM
Willing Heart Community Center
555 Martin Luther King Blvd. Newark, NJ 07102

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.

1. Welcome and Moment of Silence

Warren Poole, Committee Chair, called the meeting to order at 5:05PM 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.

2. Mission statement & Ground rules

Warren Poole, CIA Chair, read the mission statement and reminded all attendees about the Committee Ground Rules previously agreed on. Poole mentioned that the Planning Council allocates Ryan White Part A funds for 5 counties, meets every month, and is interested in hearing from people affected by HIV/AIDS who do not work for a Ryan White agency. Attendees were encouraged to be part of the CIA Committee and Planning Council. Poole emphasized that everyone could express their concerns, the type of services needed or any input during the meetings. Poole mentioned that Housing and EFA funds increased due to their input. During this agenda item, a consumer asked, "What if people cannot make it because they work?" Tania Guaman (Support Staff) stated that if the time at which meetings are happening is an issue, that feedback will be brought back to the Planning Council too.

3. Public Testimony

There was no Public Testimony

4. Approval of Last Meeting's Summary

The meeting summary was approved by members.

5. Ryan White Part A Updates

Support Staff made a presentation for Committee members which provided an overview of the Ryan White Program and the Newark EMA Planning Council. During the history portion of the presentation, a consumer emphasized the importance of recognizing that the Ryan White Program started because of a person – Ryan White – who experienced stigma, hate, and discrimination. The consumer claimed that "it is important to recognize that Ryan White was a person and not just a program we have today."

An overview of the Ryan White Program legislation and its parts was provided, with greater focus on Part A. Support Staff then asked attendees – "how many counties are a part of the Newark EMA?" Consumers helped one another to name all five counties. Support Staff explained what the Newark

EMA is and how each EMA requires a Planning Body to identify, organize, prioritize and allocate Ryan White Part A funds.

An overview of the Newark EMA HIV Health Services Planning Council was then provided as well as its various committees. The Planning Council uses data collected through surveys and other data available to identify what services people need the most and compare the data to prioritize the allocations, Support Staff explained.

Support Staff then explained the various opportunities for consumers to be involved in the priority setting and resource allocation process. Consumers can provide input at Planning Council and its Committee meetings during Public Testimony. Staff also explained that each committee is charged with a portion of the work before Planning Council approves any allocations, so if someone attends a committee meeting and give input, that person is still making an impact.

6. Old Business

Warren Poole mentioned that he is actively recruiting members for the CIA and the Planning Council. Poole then explained that during January, February and March, workshops will be focused less focused on medical education but with more focus on the Planning Council work.

7. New Business

a. **End the Epidemic Initiative Presentation**

Tania Guaman (Support Staff) also presented on the Ending the Epidemic Initiative:

- Have you heard about the Ending the Epidemic Initiative?
4 out of 14 attendees claimed they have heard about it. One of them said: they are trying to end the epidemic by 2025.”
- Support Staff explained that both the State and the federal government are supporting the Ending the Epidemic Initiative.
- The City of Newark requested \$4Million from the federal government for the Ending the Epidemic initiative, explained Support Staff, which will bring funding to Essex and Hudson County. Two consumers then asked about what the funds would be used for.
- Staff also noted that the City of Newark, in collaboration with the Hudson TGA and the State of New Jersey are developing a plan. Staff also explained that the input from this meeting would be shared with the Recipient and the Planning Council.
- ETE has 4 Pillars (GOALS). All Pillars were explained in detail and some questions were asked following the presentation.

1. GOAL#1: Diagnose all individuals with HIV as early as possible

Support Staff then asked, *how can we make sure that people who are HIV+ but do not know become aware of their status?*

A consumer suggested to “not give people a choice, just offer routine HIV testing; just like how women have to get a pregnancy test before getting an x-ray”

What do you think will be some of the challenges to routine HIV testing?

- “People not agreeing to get tested”
- People feeling “Worried about who might see me getting tested” “Stigma”
- “People not being comfortable talking about HIV”
- Not knowing where to get tested or the “site not being accessible to them”

What are your recommendations to help address those challenges?

- **Outreach:** “Meet people where they are (in their communities)”. Consumers noted that “outreach was cut.” Before, there were signs at buses and now you do not see that. Poole explained that some agencies continue to do outreach such as Hyacinth and NJCRI. Poole mentioned that opinions might create new positions in the field and their input to know what services are needed is important. A consumer mentioned “I would like to do outreach. I am a Long-Term Survivor Living with HIV for 23 years and still looking fabulous”.
- **Financial Incentives to get tested:** Poole mentioned, for instance, that some agencies give incentives for testing. Then when the person tests positive, they get an additional incentive after their first medical visit.
- Education about Mental Health and Substance Abuse

A consumer asked whether the ETE funding was for 1 year. Support Staff explained that funding will be available for 5 years. But that since the plan is under development, their input can help in drafting the plan.

2. **GOAL #2: Treat People with HIV rapidly and effectively to reach sustained viral suppression**

What do you think are some of the challenges for people being connected to a medical provider within 30 days?

- **Transportation:** “Not all agencies provide transportation. We are using our own money to get back and forth.” It was asked transportation for medical appointments or other activities. Consumer replied, “For medical appointments or not.”
- “Having other things to worry about like housing” If I do not have housing, I do not worry about other things.
- “People don’t come back after getting tested”
- “Denial”
- “Fear of the next step”, “Being in limbo”, “Feeling ashamed” “Different types of fear”
- Feeling overwhelmed – what resources would they need to get connected to care?
- “Stigma”; For instance, “On my first Doctor appointment, I was worried to be seen and was wondering if the other people in the room were also there for the same reason.”
- **Mental Health** (“A Psychologist or Therapist could help to get connected to care”). Consumer shared that people need support to get through the trauma of having been diagnosed with HIV.
- **Peer to peer Support** One consumer shared that she recently met someone newly diagnosed and that the person was scared. The consumer shared her phone number and helped the newly diagnosed to connect with local resources and services. She was this person’s support system.

What are your recommendations to help address those challenges?

- “Education, Knowledge and Courage” to do something
- A consumer shared that eventually she started “Reading to find out what is going on with me”
- “There is no straight street” People are different and deal with things different
- Awareness is the key “The more you know, the more you can deal with it and accept it”

What is Viral Load Suppression?

"Viral Load Suppression is being undetectable", a consumer said. Support Staff mentioned that viral loads must be really low to become undetectable.

What do you think are some of the barriers to Viral Load Suppression?

- Aging and other diseases that comes with age (e.g. taking more medications). "Aging is an issue."
- "Support to take medication"
- "Pill box next to nightstand to take medication before going to bed"

What recommendations do you have to help address these barriers?

- "Have all doctors in the same hospital" A consumer said "I have all my doctors in one place, so I don't have to travel and can schedule all appts in one day"
- "Support from family and friends"
- A good doctor-provider relationship "It feels better to get know to a little bit about the provider and that the provider gets to know me."
- "Having a phone alarm to remind me to take my medicine"
- Mental Health Therapist to talk about everything to find answers
- A one on one conversation with someone through Counseling

3. GOAL #3: Prevent new HIV transmissions by using proven intervention, including PrEP and syringe services programs (SSPs)

What do you think are some of the challenges to preventing new HIV transmissions?

Support Staff provided an example mentioning that individuals who take PrEP do not have a Medical Case Manager, though some agencies may offer the service, but not others.

- "I think they should have a Medical Case Manager", a consumer said.
- More agencies should offer PrEP so that if a HIV+ person has a partner who is not positive, the partner can access PrEP onsite instead of being referred to another place.
- Consumers thought that young people are not adherent to their medications so education should be provided because "PrEP does not prevent other sexually transmitted diseases."
- Consumers thought that education should be provided through "Commercials about [PrEP]." "[A] very good thing to have [is] a PrEP commercial nationally." "There should be more commercials."

4. GOAL #4: Respond quickly to potential HIV outbreaks to get needed prevention and treatment services to people who need them

What do you think are some of the challenges to responding to outbreaks?

- Consumers thought that the "Community is not working together." There should be more organization and recognize things that are right or are not.
- There should be a "leader to work with the community"

What recommendations do you have to prevent outbreaks?

- Send an "official letter to invite all community members to get tested"
- Flyers

- “Mandatory testing – Everyone should get tested for any disease that could create an outbreak”, instead of, “waiting for the outbreak to happen to do something about it.
- “Have more health fairs” – Information from Hospitals and education that can help out with any questions
- Mental Health
- Automated Phone Calls to provide information

○ **What the Newark EMA is proposing?**

- Use the new Ending the HIV (EHE) Epidemic Initiative funds to target patients in unique ways
 - Community Health Workers who can reach PLWH who are out of care and assist in return to care
 - Investigate the use of Medicaid to support housing
 - Monitor viral load suppression rates among PLH in the Newark EMA through CHAMP
- It was mentioned that some states Medicaid pays for Housing. It is being investigated if it could happen in New Jersey.

a. **Where do you learn or would like to see HIV data and information in the Newark EMA?**

- “Facebook”
- “Billboards”
- “Flyers”
- “Radio Station”
- “Government Website”

Support Staff also mentioned that the Newark EMA will be launching its website in January.

b. **What topics would you like to discuss in 2020?**

- Housing
- HIV Criminal Laws
- “Updates on the Cure for HIV”
- “Long-Term Survivors” – Poole mentioned that June is National Long-Term Survivors Month so the CIA topic will be focused on that.
- “Transportation”
- “Emotional Support Animals”

8. Announcements

Warren Poole made the following announcements and handed out flyers:

- The Holiday Party with Peter Ho CAB and the CIA will be held on Dec 20th
- Peter Ho Clinic will have its World AIDS Day on Dec. 4th

9. Next Meeting

The next CIA/CC meeting will be held on December 20, 2019 at 5 pm at St. Michael’s Medical Center located at 268 Martin Luther King Blvd. Newark, NJ 07102.

10. Adjournment

This meeting was adjourned at 6:50 pm