



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, November 17, 2021 from 5:17 PM to 7:04 PM

Video-Conference via Zoom: <https://zoom.us/j/96635953539>

Teleconference: (929) 205-6099 / Meeting ID: 966 3595 3539#

Attendees: There were 13 attendees at the meeting. Ten participated in the Zoom call. Some participants chose not to participate or arrived later during the meeting; those are listed as unknown.

Attendees by County							
Essex	Union	Morris	Sussex	Warren	Unknown	Other	Total
9	1	0	0	0	3	0	13

Support Staff: Tania Guaman and Unnati Guru

1. Welcome and Moment of Silence

Warren Poole, Committee Chair, called the meeting to order at 5:17 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

There was no public testimony.

3. Approval of the Meeting Summary from October 27, 2021

The October 27th meeting summary was sent electronically for review prior to the meeting. Poole asked for a motion to approve the meeting summary as presented. One consumer motioned and another seconded. No abstentions or oppositions.

4. Ryan White Part A Updates

Guaman provided the following update:

- The Continuum of Care Committee had conversations regarding referrals provided by one agency to another, such as from Infectious diseases program to Medical Nutrition Therapy or other support services. What are your experiences regarding how easy or difficult these referrals might be and what barriers there may be to obtaining access?
 - This topic led to a lengthy discussion regarding access to care and barriers, with some of the participants bringing up the following experiences:

- There was an issue identified with the timeframe requirement for the *Release of Information Form* for different agencies to work together for a client's care, as some people may not be able to consistently provide the information or signatures due to personal or health reasons. Delays in this form can cause a pause in their care.
- Some clients are referred to a specialist, but the specialist does not accept the insurance the client has. There was discussion regarding the benefits of the agency to work with their insurance to refer the client to a specialist who is in-network with their insurance to prevent any delays or unnecessary financial burden on the client.
- One participant needs referrals for their care every 6 months. This issue was tabled as it is likely an insurance issue rather than a care issue.
- There was a recommendation to check with one's care coordinator or case manager to ensure that all necessary forms are filled out and that there are no issues with the insurance prior to an upcoming appointment.
- Regarding determining client eligibility, Guaman brought up the new HRSA PCN 21-02 and discussed the recertification requirement and proof of eligibility to continue treatment and care. One recommendation by a member was the benefit of using the website www.SSA.gov to obtain proof of income (benefit letters to re-attest their financial status), which can be printed for appointments, as opposed to going to a Social Security office in-person for an updated letter with a recent date.

5. Old Business

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

- Continued conversations about Community Engagement
 - The group discussed the importance of community engagement, why it matters, and its impact on integrated planning, especially regarding the Ryan White system, how it works, what it requires of the CIA participants, and what can be done to make their work easier. Guaman emphasized the importance of the CIA members' and participants' lived experiences as it makes them experts, especially in relation to the impact they can make on their care when they are able to voice their experiences and make a change in the care for those living with HIV/AIDS.
 - The main topic of discussion focused on how to work towards ending stigma around HIV, which would help increase the amount of people getting tested for HIV. One member brought up the question of how many or how often their providers bring up the idea of Planning Councils and being engaged in the HIV/AIDS community in their area, to which a lot of participants replied never.
 - Some of the recommendations to increasing community engagement and awareness were as follows:
 - CIA members going to clinics to raise awareness of planning councils and the importance of community engagement
 - Writing a letter and reaching out to the Executive Committee to encourage providers in discussing Planning Councils with their clients, as they hold the highest trust of their clients

- The CIA, in collaboration with the Support Team can put together a script that they or providers can use to have clients consider joining or attending Planning Council meetings, which includes: advising the clients the Planning Council is the body that funds their care; how they would benefit with knowing how these funds are distributed; and that they would have a place to provide input on their care, as Planning Councils can connect them with people who can make a change.
- Review HRSA Guidance on Community Engagement
 - Guaman led the participants in a review of the HRSA guidance for Community Engagement, highlighting the various requirements, and going through the details of each aspect of the CIA's section for the Integrated Plan to help the participants understand what is needed of them and their scope of work.
 - The group developed a preliminary Integrated Plan timeline for the CIA committee's section of the Integrated Plan, as per the recommendation of the CPC.
 - Participants continued to discuss and add groups that should be involved in the work of the Integrated Plan to the Appendix 3 for Community Engagement. One discussion focused on how the Planning Council can engage these groups, agencies, and organizations. Some recommended methods of engagement included:
 - Hosting a lunch or dinner to bring the required and recommended stakeholders together
 - Working with the different committees to see where connections can be made and maintaining a running list of who has been engaged and where help is needed
 - Inviting providers to future CIA meetings to do a forum where participants can ask questions and share their thoughts with the providers on what needs to be done.

6. New Business

• Commemorating World AIDS Day and reflecting on how far we've come

The group took time to reflect on their experiences with HIV/AIDS from when they were first diagnosed to the present day. The committee held a moment of silence in memory of World AIDS Day and those who have passed. Some of the stories that were shared are as follows:

- One participant shared that when they were diagnosed at a younger age, there was no name for HIV/AIDS nor any treatment whatsoever. They also mentioned that there was a lot more stigma around HIV/AIDS, and very little, if any, medications to help with symptoms and delaying the progression of HIV/AIDS.
- Another participant mentioned that there were no support groups back in the day, and when there were, it focused on the topic of mortality, which felt very depressing. Now, there are support groups discussing living with HIV.
- One mentioned that they worked towards keeping their head up and looking forward through their experience. They also went to different programs to educate those around them on how far care and treatment has come for those living with HIV.

7. Announcements

- Hyacinth is hosting a World AIDS Day event: Rock the Ribbon at the Newark LGBTQ Center from 3-7PM on Wednesday, December 1st. Registration is required.
- Peter Ho Memorial Clinic's Consumer Advisory Board is hosting their World AIDS Day event on Wednesday, December 8th from 11-3PM.
- The PC Support Team will send out Calendar Invites for CIA meetings moving forward as well, with hidden email addresses, which will maintain participant privacy.
- Calendar of Meeting dates for FY 2022 were discussed, which will follow the same steps as the previous year: any dates falling on holidays will be moved up to the 3rd Wednesday of the month instead of the 4th.

8. Next meeting

The next CIA meeting will be held on Wednesday, December 15, 2021, at 5 PM via Zoom as a Holiday Social. The Integrated Planning will continue in the January meeting.

9. Adjournment

This meeting was adjourned at 7:04pm.