

Community Involvement Activities MEETING SUMMARY

Wednesday, June 26nd, 2019, at 5PM-7PM
Willing Heart Community Center
555 Martin Luther King Blvd. Newark, NJ 07103

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, welcomed all in attendance. A moment of silence was observed for all those living with and have been affected by HIV/AIDS.

2. Community Involvement Activities/ Community Conversations

Background, mission statement, goals, and ground rules - Warren Poole, CIA Chair, mentioned the background of the Planning Council and the Community Involvement Activities/ Community Conversations.

CIA Chair encouraged everyone to attend the PC and all committee meetings during Public testimony to voice the concerns and/or opinions. He mentioned that extra allocations were recently made based on consumer's survey responses. He emphasized the importance of making their voice be heard at the Planning Council meetings. Tania Guaman, Support Staff, added that the next PC meeting will be held on July 17th from 1:30pm to 3:00pm.

3. Introductions/ Icebreaker

All attendees introduced themselves including Support Staff.

4. Old Business

NMAC BLOC training – This item was not discussed.

5. New Business

- *Presentation: Long-Term Survivors*

Warren Poole, CIA Chair, held a Long-Term Survivors discussion where all attendees shared their personal stories by asking them 4 questions.

1. At what point in time of your journey did you wanted to give up? What three things did you do to keep moving forward?

Consumers agreed that a loved one's support helped them get through difficult times in their journey. Other support systems included positive affirmations, faith, self-acceptance, health education interventions, and overcoming stigma.

Most of the consumers shared that family support helped them go through their journey when they first got diagnosed.

2. What would be different if there would be no stigma to HIV?

Consumers thought that if stigma did not exist, more people would be open to talk about HIV. They also stated that there would be more support, people would

not hide their status and would get the help they need in earlier stages. They thought that there would be less depression, less violence towards PLWH and less suicide rates.

3. If a cure would be found today, what would be different in your life?

Consumers had different perspectives with this question. Some consumers felt that nothing would change in their life. Others expressed concerns about losing benefits from the Ryan White program and others, as well as, their ability to pay for their bills/housing or having to go back to work. Other consumers expressed joy at the idea of having more time by not having to go to many medical appointments or to take so many medications or to experience any side effects.

Some consumers felt that they might have a better job and even a companion in their lives. A provider joined the discussion by adding that consumers could also have a peace of mind by not having to worry about medication side effects or if more people could get infected by the disease.

4. If you had an opportunity to disclose your status to a newly diagnosed person, would you tell them your status to help them?

Consumers expressed concern in sharing their status with an unknown person. Others were willing to tell their story to guide newly diagnosed persons through the process of acceptance.

Most consumers agreed to offer the support that they did not have on their own when newly diagnosed. A provider emphasized that every consumer is an educator since they have gained knowledge about the disease, have experience the disease and have the survival knowledge to help others go through their process.

- *Ground Rules:* CIA Ground Rules were established and agreed on by all CIA members and attendees.
- *Tips to a successful Public Testimony*
Warren Poole, CIA Chair, and Tania Guaman, Support Staff, shared some tips for a successful public testimony narrative. The tips were the following:
 - Public testimony is limited to the current meeting agenda items
 - It was encouraged to speak of service categories and not specific providers. There is a difference between saying that an agency did not have the funds to help them and not being enough funds for that specific category. It was explained that all agencies have limitations on how funds are being allocated.
 - Visualize yourself speaking to the group
 - Realize your voice needs to be heard and matters - People want to hear what you have to say.
 - Focus on your message - When tell your story, to impact change give as many examples as you can.
 - Use notes to remember important points you want to share
 - Do not apologize for being nervous
 - Take a deep breath to relax and be as natural as you can

6. Announcements

Warren Poole, CIA Chair, made the following announcements:

- Join the Peter Ho CAB – incentive to join is \$100 - \$125 a month after a month of volunteering. Volunteers should attend all monthly meetings and food pantries events and will do outreach to different agencies.
- St. Michael – Peter Ho National Testing day event will be on 5th Fl. from 10am to 2pm.
- NJCRI National Testing day event will be giving free hot dog and hamburgers on June 27 from 11:30 to 3:30pm at 393 Central Ave., Newark, New Jersey 07103.
- NCHC – Summer Health Fair on June 27 from 12pm to 4pm at 444 William St., East Orange NJ.
- St. Michael – August Cook Out for consumers. Date and time will be provided at a later time.
- Peter Ho CAB will Host a Kid's day on July 17th from 5pm until 7pm at St. Michael 7th Fl. This event is for consumer children ages 6 – 13. There will be games, food and a raffle (bicycle)
- CIA will not have a meeting on July and the August meeting will be combined with the St. Michael August Cook Out event.

7. Next Meeting

On August 20, the CIA/CC will hold a Summer Cook-Out from 5-7PM at 268 MLK Jr. Blvd. Newark, NJ. This event was planned in partnership with the St. Michael's Peter Ho Clinic.

8. Adjournment

This meeting was adjourned at 6:32 pm