



# 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, June 23, 2021 from 5:03 PM to 6:30 PM**  
 Video-Conference via Zoom: <https://zoom.us/j/96635953539>  
 Teleconference: (929) 205-6099 / Meeting ID: 966 3595 3539#

**Attendees:** 21 attendees including 6 Planning Council members and 1 PC member applicant.

Attendees by County							
Essex	Union	Morris	Sussex	Warren	Unknown	Other	Total
17	2	1	0	0	0	1 (Bergen)	21

**Support Staff:** Tania Guaman and Vicky Saguary  
**Guest Speakers:** Ed Jankowski, Debbie Mohammed

- 1. Welcome and Moment of Silence**  
 Warren Poole, Committee Chair, called the meeting to order at 5:03 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.
- 2. Public Testimony**  
 There was no public testimony.
- 3. Approval of the Meeting Summary from May 26, 2021**  
 The May 26<sup>th</sup> meeting summary was sent electronically for review prior to the meeting. Poole asked for a motion to approve the meeting summary. One consumer motioned and another seconded. No abstentions or oppositions.
- 4. Ryan White Part A Updates**  
 No Ryan White Part A updates were provided.
- 5. Old Business**  
 At the last meeting, the committee discussed about the core service waiver and did some priority exercise priority ranking exercises.
- 6. New Business**
  - Discuss COVID-19 Pandemic Updates as NJ reopens; HIV and the COVID-19 vaccine

- At the last meeting, a recommendation to provide a COVID-19 Update was made. Therefore, panelists shared COVID-19 information.
  - **COVID-19 Mask Update:** As of June 4<sup>th</sup>, the mask mandate was lifted in New Jersey. Therefore, people do not have to wear a mask inside and outside public spaces. However, people older than 60 with co-morbidities such as obesity, diabetes, heart disease, smoking history, sickle cell disease are at higher risk of having a severe response to COVID-19. People Living With HIV are likely to have one or more of these co-morbidities and are at higher risk to acquire COVID-19 if not wearing a mask or are vaccinated.
  - **COVID-19 Vaccine:** The numbers of COVID-19 positive cases in New Jersey decreased once the vaccine was available. If unsure of getting the COVID-19 vaccine, weight out the information provided to make the decision.
  - **Mental Health Concerns due to the 2020 lockdown:** The isolation for over a year caused anxiety, depression for many people. Symptoms of anxiety and depression presented in different ways for different people.
  - **Things to do to feel better:** Keep in touch with friends and family through text messages, zoom calls, send letters, say hi to others even if you do not know them, watch tv shows or movies that make you laugh, reach out to mental health services including case managers, doctors to talk about your concerns, sing, rub your eyes in a circular motion for 30 seconds a few times a day or slightly press two fingers on each eye for 30 seconds to stimulate the vagus nerve and increase sense of wellbeing, body brushing from your extremities to your heart to stimulate blood flow for people who have poor circulation, and write two things that worries you and two things that you are thankful or happy for.
  - **Vitamin D deficiency for not being in the sun as much:** Symptoms of vitamin D deficiency are fatigue, moodiness, backpain, muscle pain, headaches, high blood pressure, skin issues, joint pain. The best way to prevent vitamin D deficiency is to sit outside or be in the sun for at least 15 to 20 minutes. The direct skin contact with the sun increases vitamin D in the body and can be complemented with vitamin supplements as prescribed by a doctor.
  - The mental health ties with vitamin D and testosterone levels. As men get older, the testosterone level goes down, muscle gets loss and fat gets accumulated. Providers look at the vitamin D and testosterone levels if depressed. Testosterone replacement is available, but a prostate exam will be done before starting the treatment.
  - As people get older, people tend to accumulate weight and fat under and above the muscle and have muscle atrophies. If stomach/core muscles are not used, the muscle will lose their strength and the stomach will hang. Therefore, it is important to modify the food we eat to avoid weight gain and exercise to build muscles and increase the strength in that area. But there are also medications available for weight loss that providers can prescribe.
  - Obesity contributes to a lot of the COVID-19 and HIV+ deaths.
  - Upper body strength decreases with age, people who are 65+ years might not have the upper body strength to get up after a fall. Building upper body strength can avoid potential falls.
  - There is also the risk of weight gain with HIV medication. But genetics, food and exercise also affect weight gain. There will be a presentation about this issue at a different meeting.
- Review findings about Telehealth use in the Newark EMA during a global pandemic  
Muhammed provided the Telehealth use in the Newark EMA findings and highlighted:
    - The Research and Evaluation Committee developed the Telehealth Needs Assessment.
    - Telehealth is used to provide care when doctors and patients cannot meet in-person. Before the pandemic, doctor's offices used telehealth by calling patients and giving out test results.

- The Needs Assessment tried to address the impact of telehealth on access to care during the COVID-19 Pandemic.
- The survey was available electronically and on paper.
- 135 people responded and the majority were from Essex County.
- Outpatient/Ambulatory Health, Mental Health, Outpatient Substance Use, Medical Case Management, Medical Nutrition Therapy, and Non-Medical Case Management Services were provided via telehealth by Newark EMA agencies.
- Respondents' demographics were shared. The education level prevalence was some high school or less. Most respondents were Long Term Survivors with more than 15 years with HIV.
- People reported having more in-person visits than telehealth visits. However, subsequent responses report that patients had more telehealth visits more than in-person visits in 2020. Data from the recipient's office also shows that more people had telehealth visits.
- Most people reported that would like to go back to in-person visits in 2021 but almost 40% would continue telehealth visits.
- Convenience was the number one reason people liked telehealth followed by not having to leave home (COVID-19, Transportation), quality of health care was good, among others.
- The number one problem with telehealth was having trouble with telehealth apps, followed by providers not on time.

An attendee mentioned liking telehealth, not having problems with telehealth visits, that the doctor reviews the medical records and asks if refills are needed and how the patient is feeling. However, if the patient is sick and must be examined, the patient is asked to go to the office. HRSA requires one in-person visit per year. Therefore, other visits can be via telehealth. A hybrid model (telehealth and in-person visits) can be used in the Newark EMA. "It is good to hear consumer had a positive experience with telehealth" - Postel.

- Long-Term Survivor Reflection

- Long-Term Survivor first diagnosed in 1971 when there was no name for it.
- At the time, attendee knew he was sick and kept going back to the Health Department to find out what it was. Then, heard on radio about a disease that was killing black man and told the Health Department to get tested. Results were positive for a disease that people were not surviving and there was no medication for it.
- The virus attacked lungs, hands, and head. Attendee had excruciating headaches for years.
- The attendee began jogging to build strength but also began to drink alcohol. Attendee mentioned that alcohol took away the headaches and was able function better.
- Attendee did not want to get involved with anyone or have kids since he was told he had 6 years to live. However, the attendee set in his mind that he will live 20 years with the disease.
- During the Vietnam war, attendee was waiting for draft numbers and was not afraid of Vietnam war but afraid of virus.
- Eventually, the attendee had a first child and wished to see her past the 4 months of age.
- The attendee was exercising and accomplishing things despite the diagnosis. The attendee pretended was not sick to move on with life and hid the diagnoses from family until the 90's.
- In 1997, attendee had a DWI from drinking that made him stop drinking but the headaches began.
- In 1999, the attendee was very sick, disclose his diagnosis and started taking medicine.
- Being responsible for the kids pushed the attendee to continue living.
- The perseverance of things that happened to me help me survive. "God helped me"
- "I just think maybe things that happened to me that I didn't want to happen me made me survive".

- "You have girls. You are afraid someone is going to bother them, be worried about that more than yourself, so I think, maybe a lot of that stuff made me survive".
- "And I'm here talking to you, maybe I survived, just to be here to talk to you. I don't know".
- Poole asked: What is life like for you today?
  - o "I don't think anybody gives me any breaks. They still treat me like I'm just like a regular person." They don't treat me as if you know that I am sick.
  - o "They can ask me to do all kinds of things you know, without regards to being the fact that I am sick, but I keep pushing."
- Attendee has been living with HIV for 50 years.
- **Trivia game:**
  - o What were the two names given to HIV during the late 70s and early 80s?
    - Attendee mentioned GRID (Gay-Related Immune Deficiency).
    - Another attendee mentioned the package. The package was the slang name.
    - The other response was the game plan or game leg.
  - o Attendees received gift cards for answering the trivia and Long-term Survivor received a special gift for sharing testimony.
  - o All attendees counted down to know how many years they have been living with HIV. The attendees who have been living with HIV the most and the least received a gift card.

## 7. Announcements

- The Health Resources and Services Administration (HRSA) provides funding for the Ryan White Part A Program in the EMA. The Site Visit for Ryan White Part A Clients will be virtual on July 12 at 3pm to 4:30pm. The goal of the site visit is to hear the community perspective on the Planning Council and services.
- HRSA received a list with consumers' information and will send the meeting invitation to participants. HRSA will be using Teams, which it is like zoom. However, Support Staff and the Recipient's office is working with HRSA to allow participants to use Zoom since Newark EMA participants are more familiar with Zoom.
- Part A Clients who participate will receive a \$50 gift card as incentive.
- A Song "That's what friends are for" by Elton John, Gladys Knight and Stevie Wonder was played to honor Long Term Survivors.

## 8. Next meeting

The next CIA meeting will be held on Wednesday, July 21, 2021, at 5 PM via Zoom.

## 9. Adjournment

This meeting was adjourned at 6:30pm.