

Community Involvement Activities MEETING SUMMARY

Wednesday, September 25, 2019, at 5PM-7PM
557 Clinton Ave. 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, those who have passed, and those affected by HIV/AIDS.

2. Community Involvement Activities/ Community Conversations and Planning Council Overview

Warren Poole, CIA Chair, provided a Planning Council and Community Involvement Activities overview. Poole explained that the NEMA Planning Council and CIA would like to increase consumer's participation at monthly meetings. Poole also mentioned the importance of participating in Planning Council meetings and during the Public Testimony item on agendas. Poole, CIA Chair, stated that he has been an HIV advocate for 32 years and that he continues to be an active member of the NEMA Planning Council.

Poole explained that the Newark EMA HIV Health Services Planning Council prioritizes and allocates Ryan White Part A services for people infected and affected by HIV/AIDS. Poole, CIA Chair, noted that housing and transportation funds were increased because of consumers' input. Lastly, he encouraged everyone to participate in the Planning Council and introduced Support Staff to all attendees.

Tania Guaman, Support Staff, asked some the following questions to consumers to get an insight of how much they know about the Ryan White Program and the Newark EMA HIV Planning Council.

1. Support Staff asked attendees to raise their hands if they lived in Union, Essex, Warren, Morris, or Sussex Counties. 3 people were from Union and more than 50 people were from Essex (majority in the room). There no representatives from Warren, Morris, or Sussex.
2. Support Staff asked if attendees knew why the Ryan White Program started. One consumer replied he knew about it and stepped to the middle of the room to share with everyone. The attendee explained that there was a 13-year-old kid name Ryan White who was infected with HIV through a Blood Transfusion. He said that this happened in the 80's when there was a lot of HIV stigma related to the disease. He mentioned Ryan White was bullied and discriminated in school and was eventually expelled from school. His mother took this issue to the supreme court and after he passed away, the Ryan White Act was developed. The consumer also mentioned there is a documentary about Ryan White and recommended everyone in the room to watch it.

3. Support Staff asked attendees to mention the parts (A, B, C,D) of the Ryan White Program that are funded in the Newark EMA. 5 consumers said: Ryan White Part A. 3 said Ryan White Part B. 3 said Part D. Support Staff clarified that the Planning Council is only involved with Ryan White Part A, which funds HIV/AIDS care and treatment services in the Newark EMA.
4. Support Staff then asked attendees about the role of the Ryan White Part A Program. Some attendees suggested that Part A gives funding for medical services. Others said that it provided funding for housing. Support Staff explained that the Ryan White Part A Program provided funding for both core medical services and support services. All Ryan White Part A service categories were mentioned.
5. Support Staff then asked: "What is the Newark EMA Planning Council? One consumer said that the Planning Council provides the funding for HIV Services in Newark. Support Staff explained that the Planning Council prioritizes, allocates funding for services, and prepares directives for funding in the Newark EMA. Staff also explained that the Council works closely with the City of Newark-Ryan White Office, who selects sub-recipients and monitors their work.
6. Support Staff asked: "What is the role of the Planning Council? One person answered that the Planning Council allocates the money from the Ryan White Program. Guaman mentioned that that was just part of what the Planning Council does. She mentioned that the Planning Council assesses the Needs of services within the Newark EMA, develops Standards of Care, listens to consumers' input, gathers information about service priorities and more. Staff emphasized that consumers' voices matter and that it also counts for funding allocations.

3. Presentation: HIV and Aging from Symtuza

Presenters talked about the natural changes that occur with age in an individual. They also emphasized that those changes can affect everyone's overall health specially when taking HIV medications. The Presenter stated that aging can cause some health issues like diabetes, heart disease, high blood pressure, arthritis, among others. The presenter mentioned that aging affects vital organs like kidney, bones, liver, among others. She stated that with a healthy diet and exercise, the effect aging has on an individual can be controlled. However, the effects aging has on an individual living with HIV is greater than for those who do not have the virus. She mentioned this was because People Living with HIV have a weaker immune system than those not living with the virus. The presenter suggested that the patient's HIV treatment can be changed to slow down vital organ deterioration. She emphasized that any change in medication should be consulted with a primary care provider.

The presenter also talked about adherence to medications. She emphasized that the medication needs to be taken regularly since it protects the body from the internal damage the virus causes. She also mentioned that this damage cannot be seen but it does not mean it is not happening. Presenter also mentioned that drug resistance can occur even if patients have missed only a few doses of their medication, which it is another reason adherence to medication is important. She asked attendees about some reasons why they would stop taking their medications. Consumers replied that it was mainly due to side effects. Other consumers replied that they sometimes forget to take their medication on a regular basis. One consumer added that when the person forgets to take their medication, they can still take it when they remember. That consumer also commented that it is better to take the medication a few hours later than to miss a whole dose. The presenter agreed and emphasized the importance of taking the medication on a regular schedule to prevent drug resistance. She stated that patients need to take their medication consistently for it to work effectively. Presenter encouraged everyone to talk to their providers about medication side effects

instead of not taking their medications due to their side effects. The Presenter also mentioned that not adhering to the medication can cause the virus to mutate, so the medication becomes less effective. However, she stated that some medications have a high barrier to resistance and can continue to work even if the virus starts to change.

The Presenter stated that Symtuza is a complete treatment in one pill to treat HIV-1 infection in adults who have never received HIV medicines in the past, or as determined by providers after meeting certain requirements. Presenter mentioned that patients need to take Sumtuza daily, at the same time every day and with food to maintain efficacy as well as all other medications. Presenter mentioned one more time the importance of taking the medication at a regular time for more efficacy. Presenter mentioned that Symtuza is a medication with a high barrier to drug resistance and allows the medication to keep working even if the virus tries to outsmart the medication. She also stated that Symtuza may have less impact on bone and kidney health than other HIV treatments. After the presentation, presenter took their time to answer some consumer's questions individually.

4. Announcements

Warren Poole, CIA Chair, made the following announcements:

- Thanked the presenters for providing this information to consumers and for the food provided.
- Thanked Providencia Rodriguez for attending the event and bringing consumers with her to the event.
- The next CIA meeting will be held on October 23rd at the Willing Heart Community Center with a topic of "HIV and Aging".
- Peter Ho CAB will host a World AIDS Day on December 4th at St. Michael Medical Center.
- NJCRI will host a World AIDS Day event on December 7th.

Dinner was served after announcements.

5. Next Meeting

The next CIA meeting will be held on October 23, 2019 at Willing Heart Community Center located at 555 Martin Luther King Jr. Blvd. Newark, NJ 07102.

6. Adjournment

This meeting was adjourned at 7:00 pm