

CONSUMER INVOLVEMENT COMMITTEE

February 9, 2024
10:00 AM - 12:00pm
Meeting Minutes

MEMBERS PRESENT:

Susan B. Co-Chair
Arthur B.
Barbara G.
Denise R.
Gerard S.
James C.
Joseph P
Juanita C-F
Lance M.
Pamela B.
Roni W.
Tyrone B.

MEMBERS ABSENT:

Cathy M, Co-Chair
Angie P.
Clara C.
Eileen B.
Ernest B
Gavis C.
James H.
John V.
June T.
Nancy D.
Patricia R.
Paul B.
Traci S.
Wendy A.

GUESTS

STAFF:

JoAnn Henn
Georgette Beal
Myra Alston
Nancy O'Keefe
Katie Ramirez

Absent

I. Welcome/Introductions

Susan B. Co-chair. opened the February 9, 2024, meeting at 10:10 with a welcome and introductions. She then requested a moment of silence to remember those whom we have lost, and those still living and struggling.

Denise R. and Tyrone B. received their World AIDS Day award.

II. Consumer Survey

A consultant is working on updating and revising the 2024 Consumer Survey for clarity and relevance. The information gathered from this survey will help the Planning Council to better meet the needs of Long Islanders with HIV. A competitive application will be submitted this year, so the information gathered from the survey is very valuable in requesting and allocating funds for the next three years. This survey format is similar to the 2019 Survey, with added questions regarding aging, housing, and homelessness, to reflect the concerns of the region. Ms. Ramirez requested help with administering the survey. As was done previously, funded providers

and peers will be asked for assistance with helping clients complete the survey. At this meeting, four CIC members offered their assistance. The goal is to receive 500 completed surveys. This survey should be filled out by anyone with HIV/AIDS living in Nassau or Suffolk County and their caregivers.. This survey should be filled only once per person. All information will be kept confidential. There is an expected launch date of March 1 with a completion deadline of May 31, 2024. The consultant will write a final report on the survey findings. More details to follow.

III. Orientation Session

There was a mini orientation describing the CIC Committee, its role and responsibilities, ground rules for meetings, and the transportation process. The value of consumer leadership and involvement was stressed throughout the presentation. A copy of the orientation was distributed to the committee members to be used as a reference. This orientation was an opportunity to educate new members as well as offer a refresher for current members.

The Consumer Involvement Committee is a standing Committee of the Planning Council that addresses issues affecting PWH from a consumer point of view. Members live in the Nassau-Suffolk region and help to increase awareness of important community issues related to the epidemic.

There is a legislative requirement that 33% of the Council membership must be unaligned consumers, which means that the consumer does not have any affiliation with a funded agency, either by employment or sitting on an agency board.

Consumer leadership provides contact between the Council and the community it serves, ensuring that services reflect client needs, while helping the Council to understand the diverse service needs of the community. The different ways that consumers can get involved were discussed, especially committee participation. Much of the work is done at the committee level. CIC roles and responsibilities include but are not limited to:

- Identifying service barriers
- Conducting needs assessments
- Participating in quality management and evaluation of regional services
- Developing and implementing annual workplan goals.

The ground rules for meetings revolve around respect for the co-chairs and members, such as raising your hand and waiting to be acknowledged, not talking over each other, and respecting the opinions of others. Following the agenda helps to guide the meeting and keep it on track. Transportation can be arranged to attend meetings. There are two transportation agencies, one in each county. The Planning Associate is informed that transportation is needed, preferably a week before, and transportation is arranged. Pick up is usually scheduled for an hour before the meeting time. Agency phone numbers were given for consumers to call should a problem such as lateness occur.

The simple goals are to work together, respect others, and see outcomes. It's easier if we all pull together.

IV. CIC Workplan

The CIC workplan is reviewed annually. The objective of the workplan is to increase active consumer involvement by assisting in the recruitment of PWH members to the Council and its committees; increasing public awareness of important community issues related to the epidemic; and providing a safe place for consumers of Ryan White services to share their experiences. There are four sections to the CIC work plan: goals, proposed activities, timelines, and targeted outcomes.

Outreach/Engagement-The goal is to educate the community about the Planning Council, the role of consumers, and increase active consumer participation, engagement, and retention. In addition to some of the proposed activities of developing an outreach plan for maintaining and retaining PWH on Planning Council and its committees, conducting an annual orientation for members and mini-orientations as needed for new members, and representing the Council at community events such as HIV Testing Day, there are plans to increase the committee's social media presence. The proposed activities are ongoing. Targeted outcomes include recruit (5) new members each year, retain at least (3) new members, and increase consumer attendance at CQM and SAP meetings by 10%.

Needs Assessments/PSRA Process-The goal is to share consumer perspectives, assist with identifying service gaps, increase awareness of regional needs and special populations on Long Island, and increase consumer participation in setting Part A priorities and allocating resources in the region. One of the proposed activities is participating in the 2024 Consumer Survey. Consumers reviewed and provided input and are spreading the word about the Survey to increase completion rates. In addition to the PSRA, other activities include a review of the 2024 HIV System Assessment, suggestions about needs assessments that should be conducted in the region, and participation in the community forums with a targeted outcome of increasing the number consumers who attend the Community Forums to 100 in 2024.

Trainings/Development -The goal is to increase awareness and educate the community and stakeholders about HIV/AIDS issues as well as improve advocacy skills for CIC Committee members. Proposed activities include developing a list of training topics and conducting three CIC trainings during 2024. Some of the training topics suggested were, aging with HIV, insurance updates (Karen Timour will be contacted about her availability to present), the HIV Stops with me campaign, and healthy eating/nutrition.

Another proposed activity was the planning and hosting of one major consumer training/presentation during the year; an event for approximately 50 consumers Date to be determined.

V. World AIDS Day 2024-

The post-2023 World AIDS Day event discussion began. This 2023 celebration was the first in person event since 2019. A new venue, Captain Bill's in Bay Shore, was booked for the event

and attendees seemed pleased with the establishment. The committee would like to reserve it for the 2024 World AIDS Day event. More planning is scheduled for the April CIC meeting to determine the date, theme. Proposed outcomes are to have 150 attendees, raise at least \$10,000 through sponsorships and raffles to pay for the event, and secure at least \$1,000 in donations for the raffle baskets.

VI. Announcements/Adjournment

There were no announcements.

The motion was made by Pam B. and seconded by Denise R. to adjourn the February 9, 2024, Consumer Involvement Committee meeting. **All in Favor-Motion carried.**