

CONSUMER INVOLVEMENT COMMITTEE
February 8, 2019
10:00 AM - 12:00 PM
CONFERENCE ROOM, UNITED WAY OF LONG ISLAND, DEER PARK, NY

<u>MINUTES</u>		
<u>MEMBERS PRESENT:</u>	<u>MEMBERS ABSENT:</u>	<u>GUESTS</u>
Clara C., Co-chair	Angie P	
Marci E. Co-chair	Denise R.	
Arthur B.	Ernest B.	
Eileen B.	James H.	
Gaius C.	Juanita C-F	
James C	Keith A.	
Joseph P.	Lance M.	
June T.	Paul B.	
Kevin M.	Robert S.	
Nia J.	Traci S.	
Richard G.	Wendy A.	
William D.		

STAFF:

Georgette Beal
JoAnn Henn

I. Welcome/Introductions

Clara C. called the meeting to order at 10:10 am. She welcomed everyone and introductions were made. A moment of silence was observed.

II. Approval of October 12, 2018 Minutes

The October 12, 2018 minutes were approved with the following corrections:
Member attendance corrected. Northwell's holiday party was December 7, 2018 and the World AIDS Day event was November 30, 2018 in the afternoon.

A motion was made by Kevin M. and seconded by William D.

9 Approved 0 Opposed 3 Abstentions

III. CAB Update/Regional Trends

The purpose of a CAB (Consumer Advisory Board) is to learn what is going on at the different agencies, including experiences accessing care. This information is often shared with the CIC Committee to help inform planning and to address barriers to care.

- Clara C. Co-chair of the CIC committee, has recently been elected as chair of the Northwell CART Consumer Advisory Board. William D. has accepted the position of secretary of the CART CAB. The next CART meeting is March 26, 2019.
- Marci E. informed the committee that Thursday's Child is administering the Consumer Survey, if any consumer still needs to complete it.

Questions regarding the government shutdown and its effect on services were raised. One committee member said that January's food stamps included February's in anticipation of the shutdown. Food insecurity concerns were discussed. Members shared that a list of food pantries is available through the NUMC CART and using 2-1-1 as a resource as well.

Marci E. spoke about the ADAP and Hep C conference she had attended. She was shocked by the amount of pharmaceutical greed adding that the high cost of medications causes people to search elsewhere for less expensive alternatives. She recommended visiting the website, www.safemedicines.org for more information, which includes list of legitimate pharmacies. There is also a newsletter to which you can subscribe.

Marci felt that in comparison to other states and regions, New York State is good in terms of medications and waiting lists. The increase in Hep C cases was disturbing, however there will be new medications in addition to Harvoni, the current treatment of Hep C. Another website cited is www.adapadvocacyassociation.org whose mission is to promote and enhance AIDS Drug Assistance programs and improve access to care for persons with HIV/AIDS.

IV. Consumer Input/Needs Assessment

Approximately 100 Consumer Surveys have been completed. Ms. Ramirez is available after the CIC meeting, if anyone would like to complete the Consumer Survey today. The goal is to have 500 participants.

Dates for the 2019 Community Forums are being confirmed. A copy of the confirmed forums is available. Thanks to those who have offered to facilitate at these events. The location of the eastern forum has been moved to Parrish Memorial Hall, Stony Brook Southampton Hospital, Southampton. NUMC and LIGALY have yet to be scheduled. In total, there should be seven community forums scheduled for 2019.

VI. Goals and Objectives for 2019-

There was discussion regarding the type of trainings and presentations that the CIC committee members would like to see in 2019. Ms. Osk, Esq. from Nassau Suffolk Law Services will be presenting at the April CIC meeting and speaking about how employment may impact benefits. At this meeting, a request was made to see if E5 housing could also be discussed. Ms. Henn will contact Ms. Osk to see if that is possible or if it would be better to have this topic as a separate presentation at a later date.

Other training topics for future meetings include:

- Housing -(including E5), HOPWHA, and LI Housing Partnership
- Exercise and nutrition program and services. This topic generated much interest. Members shared that exercise and fitness programs may be available through local libraries. Planet Fitness was suggested as an affordable alternative. Gyms may offer trial memberships, and some insurance companies may cover some of the cost through programs such as Silver Sneakers, which is offered through Medicare. Kevin M. suggested starting a walking club. Nutritionists from both Nassau and Suffolk County can be contacted to give presentations, provide resources, and answer questions.

- Trainings on education, prevention, and treatment of bed bugs, ticks and Lyme disease was cited as being a growing issue/concern.
- Peer Certification Program – Although there has been a good amount of graduates of the Peer Certification Program, some new committee members may not be aware of the program and others who know about the program may need more information. The currently certified peers can speak about their experiences.

In addition to trainings and presentations, Ms. Beal asked the committee if there were any events they would like to have. Northwell hosts the consumer picnic during the summer, but a consumer luncheon/training session may be something that can be planned.

VI. Announcements/Adjournment

- LIAAC is sponsoring an evening of art and discussion about issues of stigma and safety critical to LGBTQAI Youth on Long Island. The event will be held tonight, February 8, 2019 at 60 Adams Avenue in Hauppauge from 6pm-9pm
- Nia informed the committee members that Robert S. has pneumonia.
- Ernie is recovering from surgery, please sign his get well card.
- Marci E. has informed the committee that another fun support group event for Long Term Survivors (LTS) is being planned. Details to follow.
- Nancy told the committee about a part-time HIV peer educator position at Planned Parenthood.
- Planning for 2019 WAD event will soon be underway, with the first meeting to be scheduled sometime in March.

A motion was made by James C. and seconded by Kevin M. to adjourn the February 8, 2018 Consumer Involvement Committee meeting. **All in Favor-Motion carried**