

CONSUMER INVOLVEMENT COMMITTEE
March 3, 2017
10:00 AM - 12:00 PM
CONFERENCE ROOM, UNITED WAY OF LONG ISLAND, DEER PARK, NY

MINUTES

MEMBERS PRESENT:

Nancy D. Co-Chair
Arthur B.
Clara C.
Marci E.
James H.
Kevin M.
Joseph P.
Angie P.
James C.
Traci S.

MEMBERS ABSENT:

Lance M. Co-Chair
Keith A
Wendy A.
Traci S.
Ed M.
Glenn L.
Juanita C-F
Clement W.
Margret H.

GUESTS

John G.
Lissette V.
Ernest B.
Richard G.
Reynaldo G.
Sandra H.
John V.
Clifford T.
Gauis C.

STAFF:

Georgette Beal
JoAnn Henn
~~Victoria White~~
Stephanie Moreau

I. Welcome/Introductions

Nancy D. called the meeting to order at 10:10 am. She welcomed everyone, acknowledging the new faces at the table and introductions were made. There was a moment of silence to remember those living and those we have lost.

II. Breakfast- Mr. John Galletta from The AIDS Health Foundation generously provided breakfast for the committee. He provided an overview of the AIDS Health Care Foundation and described the different services available from the pharmaceutical company. This was followed by a Q & A.

III. Approval of November 4, 2016 Minutes

It was decided to table the minutes to allow enough time for Ms. Sandra Houston to speak about the Ryan White Part A Mental Health Assessment Project.

IV. Ryan White Part A Mental Health Assessment Project-

In preparation for this meeting, Mental Health providers were contacted and asked to recommend consumers to participated in the Mental Health Assessment focus group. Consequently, a number of guests were present to provide input regarding Mental Health Services on Long Island.

Ms. Sandra Houston, Principal at Pivot Principles, LLC facilitated the presentation. Prior to this meeting, Ms. Houston conducted interviews with Mental Health providers regarding care and

available services. The purpose of the Mental Health Assessment Project is to gather data and information in order to create a needs assessment regarding care and access to Mental Health services. By identifying challenges and barriers, the needs of consumers can be better addressed.

Consumers agreed that while primary care is the most important service, access to Mental Health services is also necessary for many individuals. Unfortunately, a number of issues and various challenges interfere with accessing this care.

Findings:

- Funding issues- Many agencies are not necessarily funded for Mental Health, but are funded for Substance Abuse. They are two separate issues and many agencies treat them together. An individual should not have to have a substance use disorder before the mental issue is addressed. Conversely, not everyone who needs Mental Health services needs Substance Abuse support as well. There are not enough mental health services available to consumers.
- Transportation issues- The geography of Long Island stipulates the need for transportation. Public transportation continues to be an issue on Long Island. Nassau County has reduced and in some cases, eliminated a number of bus stops. In both counties, bus service is limited in terms of hours of operation and proximity to the destination. Suffolk County public transportation is even more challenging; bus service is non-existent after a certain hour. If individuals are unable to get to their appointments, they can't access the care they need. Transportation resources may have limits in terms of funds and the number of trips available per client.
- Location- There are not many agencies offering mental health services, they are few and far between. In Suffolk County, the only Ryan White funded agency providing this service is in Southampton, on the easternmost part of Long Island. Hispanic Counseling Center offers some Part A MH services but they are primarily for the undocumented. Those living in Suffolk County may decide to access care in Nassau County, although closer, it can still be a significantly long trip.
- Language- Hispanic Counseling in Nassau County offers bi-lingual services. Not many agencies are able to serve Spanish-speaking clients, so it is a beneficial resource.
- Access to services- Many individuals are finding that they have to *go around the system* in order to access these services. For example, while their status may not be the initial reason for the medical visit, it will still be able to be addressed by the health care professional during the scheduled visit.
- Crisis situations –Questions arose as to the course of action in case of an emergency? An emergency, by its very definition, is an urgent and often unplanned situation. These situations rarely occur at a convenient time, say during regular business hours. What options are available to the consumer when such a situation occurs?
- Integration- Team based care, the trend to integrate medical and health services into a one-stop place to receive care, was not always viewed as a positive thing by the focus group participants. Unlike the providers, the majority of whom agreed with this model, many consumers expressed concerns about confidentiality and delivery of services. They were not comfortable with having their personal MH information shared with others, especially peers. They were of the opinion that separation provides more choices and takes into account staff likeability. Others said they would prefer to receive these services in a non-hospital setting.

- Psycho-social support- Psycho-social support is vital to providing quality Mental Health services.

Those present reported that the closing of FECS had quite a significant and negative impact on their mental health support and services. Consumers stated that FECS provided stability and support. FECS was credited with helping consumers *stay on track* regarding appointments, medications, and support groups. There were various education programs available to them. Many felt that the closing of FECS left a gap in care with nowhere for them to go resulting in expressions of frustration and concern about *falling through the cracks*, feeling forgotten, and not having any support. Agencies that have closed have not been replaced.

Suggestions-

- There should be Mental Health services specifically for consumers as well as their partners, who are also impacted by the disease. As one consumer stated, *HIV is a problem all on its and everyone has a different story*. Many individuals are struggling with depression.
- As this population is aging, there is a need for support groups specifically for long time survivors, focusing on quality of life.
- Mental Health professionals should listen more and not be so quick to prescribe medications. What is needed is sometimes more than a prescription.
- Both individual and group sessions are needed. People differ as to supportive needs, some do well in groups, and others need support on a one-to-one basis. Both options should be available.
- More social events and opportunities, to get out of the hospital setting and frame of mind; to support and connect with each other.
- Creation of a Consumer Appreciation Day.

VII. Other Business

No other business was discussed.

VII. Announcements/Adjournments

A motion was made by Marci E. and seconded by Arthur B. to adjourn the March 3, 2017 Consumer Involvement Committee meeting. **All in Favor-Motion carried**