

**NASSAU-SUFFOLK HIV HEALTH SERVICES PLANNING COUNCIL
BOARD ROOM, UNITED WAY OF LONG ISLAND, DEER PARK, NY**

November 13, 2019

9:30 am – 11:30 am

MINUTES

MEMBERS PRESENT

Felix Ruiz, Chair
Traci Shelton, Vice-Chair
Gloria Allen
Ilvan Arroyo
Arthur Brown
James Colson
Clara Crawford
William Doepper
Nancy Duncan
Lawrence Eisenstein, MD
Juli Grey-Owens
Kevin McHugh
Teresa Maestre
Cathy Martens
Johnny Mora
Victoria Osk, Esq.
Angie Partap
Rev. Loring Pasmore
Joseph Pirone
Jacqueline Ponce-Rivera
Erik Rios
Anthony Santella, DrPH
Katelin Thomas
James Tomarken, MD
John Van

MEMBERS ABSENT

Lisa Benz-Scott, PhD
Tania Chiu
Martine Michel-Toure
Denise Ragsdale
Jessica Totino
June Tappan

GUESTS

Andrea Ault-Brutus
Febuary D’Auria
Lauren Gentile
Ernesto Hernandez
George Marzen
Scott Peterson
Margaret Sukhram
Brett Wargo

UWLI STAFF

JoAnn Henn
Myra Alston
Stephanie Moreau
Katie Ramirez
Victoria White

COUNTY STAFF

Nina Sculco

I. Welcome and Moment of Silence

Mr. Ruiz, called his first meeting as Chair to order at 9:45 am. He welcomed everyone and introductions were made.

II. Public Comment

Dr. Eisenstein informed the Council that the new office of Health Equity was launched on Friday. There was a wide a search to find someone to fill the position and the position has now been filled by Dr. Andrea Ault-Brutus

III. Approval of September 18, 2019 Minutes

Ms. Nancy Duncan was marked as present at the September meeting.

Ms. Martens made a motion to accept the minutes as corrected, which was seconded by Ms. Osk.

15 Approved 10 Abstentions 0 Opposed - Motion Carried

IV. Administrative Update

The Recipients Grievance Procedure was amended and a draft copy was sent to United Way for review. Reallocation forms were sent to Part A agencies and are due back in December. Agencies will have the opportunity return any unspent funds and to request additional funds during this process.

V. Committee Reports

Executive Committee-

Ms. Shelton reported on the November 4, 2019 Executive Committee conference call. During this meeting, the November Planning Council agenda was approved. Congratulations were extended to Mr. Ruiz and Ms. Shelton as they begin their terms as Planning Council Chair and Co-Chair. Congratulations were also extended to Mr. Pirone on behalf of his acceptance of the CQM Co-chair position.

Ms. Beal provided a brief administrative update regarding upcoming activities including reallocation of funds, (CFAs) continuation funding applications, and (RFPs) requests for proposals..

The Planning Council is responsible for the training of members on their roles and responsibilities. To that end, it was decided that a Member Needs Assessments Survey will be distributed to Planning Council members at the November meeting in order to determine which topics to include and emphasize in order to better serve training needs. Plans to engage agency participation in Planning Council membership recruitment were also discussed.

The next Executive Committee Conference call has been scheduled for January 6, 2020.

Strategic Assessment & Planning Committee-

Ms. Partap reported on the SAP meeting that took place on November 6, 2019. At that meeting, the final results of the Consumer Needs Assessment were presented to the committee in a PowerPoint presentation. A breakdown of responses included gender, age, race/ethnicity, income level, housing status, transmission mode and reported co-morbidities. Respondents were also asked what changes they would like to see in order to improve services for PLWHA. This information will be shared, in further detail with the Planning Council.

The committee reviewed the work plan from the 2017-2021 NYC Integrated HIV Prevention and Care Plan, which listed goals, objectives, and strategies. In addition, an overview of the FY2020-2021 Early Identification of Individuals with HIV/AIDS (EIIHA) Plan was also distributed for review. Both plans will be discussed in further detail at the next SAP meeting, which is scheduled for January 15, 2020.

Consumer Involvement Committee-

Ms. Crawford reported on the October 11, 2019 CIC meeting. A simplified review of Robert's Rules of Order was conducted, followed by a committee decision-making activity based upon those rules. Consumer recruitment was discussed. Two consumers ended their second Planning Council term at the end of September and two more consumers will be ending their second term at the end of September 2020. This is important because of the HRSA requirement that 33% of Planning Council membership be unaligned consumers. Consequently, consumer recruitment strategies were introduced and further discussion will continue at the February 2020 CIC meeting.

An update was also provided on the 2019 World AIDS Day event scheduled for Friday, December 6, 2019.

Clinical Quality Management Committee

Mr. Pirone, reported on the CQM meeting that was held on October 24, 2019. He is assuming the role vacated by Ms. Shelton as she begins her term as Planning Council Vice-Chair. The oral health brochure was reviewed and final changes were made. The brochure will be finalized in house by United Way's marketing department.

The meeting continued with an overview of the findings of the 2019 Administrative Mechanism Survey and an update on the latest data that was submitted by the EMA through the HRSA HIVQM module was given to the committee. Since there were no Planning Council applications to review, the Membership Subcommittee did not meet and the meeting was adjourned.

The last CQM meeting of 2019 is scheduled for November 21, 2019.

VI. Final Results of the 2019 Consumer Needs Survey

Ms. Ramirez shared the results of the 2019 Consumer Needs Survey. The last Consumer Needs Survey was administered by an outside consultant in 2014. The survey has been administered since 2007 and the questions were developed, reviewed and amended by the SAP Committee as needed. Ms. Ramirez thanked the (16) agencies that participated and the certified peers whom she credited with helping to engage a larger audience. The goal was for 500 participants, 481 responses were collected, of which 467 were viable. In order to participate in the survey, participants had to be HIV positive and reside in Nassau or Suffolk counties. The survey was administered through by various methods including; on-line through Survey Monkey, at different agencies with the help of a peer if needed, or over the phone with Ms. Ramirez. The survey was available in both English and Spanish.

2017 EPI Data-The demographics of the survey respondents was compared to number and percentage of HIV positive individuals in the Nassau-Suffolk region as of 12/31/2017. Categories included, Sex at Birth, Race/Ethnicity, Age Group and Risk Category. Answers are self-reported. There were more male respondents than women. Of the 467 respondents, 274 (59%) were male, 181(39%) female, 5(1%) identified as Transgender (male to female). No one reported Transgender (female to male) and 7(1%) chose not to answer the question. Respondents self-reported as White/Caucasian 39%, Black/African-American 35% and Hispanic/Latino 28%.

Age Strata-the largest percentage of 2019 respondents was 33% in the 50-59 range; 25% in the 60-69 range; and 16% in the 40-49 range. Interestingly, as compared to 2014 data, in 2019 the 40-49 age range was down 4%, the 60-69 age range increased by 10% and the 70+ was 3% higher than the previous survey, which clearly illustrates that individuals are living longer with the disease. More than half of respondents are over the age of 50.

Monthly income- 21% (which equates to 90 respondents) reported a monthly income of between \$1,000 and \$1,499. Reports of income levels \$3,000+ more than doubled from 2014. This may be attributed to more consumers returning to school, as well as becoming certified peer workers.

Housing Status- there is a need for available and affordable housing options for PLWHA on Long Island. A significant number of individuals have experienced homelessness. The breakdown is as follows:

- 7% reported being currently homeless.
- 6% reported being homeless in the last two year, but not now
- 11% reported being homeless over two years ago, but not now.

Housing or the lack thereof, continues to be of concern as evidenced by the results of this survey. When asked about housing situations, the choices included owning or renting home or apartment, living in a parent's home or apartment, renting a room, living in someone else's home or apt, living with a roommate or partner, differentiation between homeless (on streets) or homeless (in shelter), PLWHA group home, group home not PLWHA, and other which can include living in a car, shed or couch-surfing.

The number of individuals who rent or own their home/apartment is slowly rising, 56% reported owning or renting home or apt, up 3% from 2014. The number of those renting a room decreased, from 12% to 5.2% which may explain the slight increase previously mentioned. However, the percentage of individuals living in a parent's home rose from 6% to 13%. Other increases include, Homeless (on streets) up from 0.8% to 2% and homeless (shelter) up from 1.2% to 3%, PLWHA Group Home rose from 1.4% to 2%. This is not surprising, when considering the high cost of rent and lack of affordable housing. It should be noted that the lack of affordable housing was also mentioned at all of the 2019 community forums.

The percentage reported living with a roommate was more than halved, down from 2.2% and no one reported living with a partner, which was reported as 3.8% in 2014. No one reported living in a drug or alcohol treatment housing situation, a nursing home, psychiatric treatment center or jail. 1% responded a sober house situation, and 2% replied other, without further explanation. (In past surveys, housing situation responses included nursing home and jail). It was suggested that the wording be reviewed for clarity, as in the case of roommates and partners. Are all partners roommates? Does there need to be a distinction? Also recommended was a future presentation by the LI Coalition for the Homeless to inform and address the homelessness issues.

Transmission Mode and Sexual Orientation- not necessarily for the newly diagnosed, exposure as follows: 36% MSM; 7% IDU; 44% heterosexual; 5% transfusion; 3% perinatal; 1% sexual assault; 3% other/unknown.

A total of 36 respondents were newly diagnosed; 26 in 2018, 10 in 2019 (24 males, 12 females). Transmission 47% heterosexual, 36 MSM, 6% transfusion, 3% MSM/IDU, other and Unknown.

When the results of the Top 10 reported Comorbidities were shared with the SAP Committee, members were surprised not to see cancer, heart and kidney problems listed. While these comorbidities exist they ranked, 12% for heart problems and 11% for both kidney problems and cancer.

- A breakdown of Sexually Transmitted Infections was provided, differentiating between *ever diagnosed* or *within the last year*.
- Age and Medication Adherence –*Are you currently taking HIV medications?* The vast majority are taking HIV medications. Of the 467 responses, only 8 replied *No*, citing undesirable side effects, or too costly, the remaining 6 responses did not specify a reason for not taking their medication.
- Regarding Medically related services reported as needed but couldn't get- dental services topped the list. It should be noted that this survey was completed before the Nassau Oral Health RFP was approved. These services was ranked in order; next was eye care, home health services, mental health/emotional counseling services and medical case management.
- Non-medically related services, reported as needed but couldn't get were assistance with basic needs. Ranked as 1. Money to pay mortgage and rent; 2. Money for utilities; 3. Assistance with co-payments; 4. Food bank; 5. Help with finding and keeping housing.
- Mental health- 50% of respondents reported feeling anxious, depressed or felt they have a mental issue; 38% reported being referred for a MH evaluation; 36% said they were diagnosed with a mental health condition.

- Substance use- 3% think they needed treatment for drug or alcohol problem. There is continued reluctance to seek treatment for substance use or even acknowledge the need for treatment, 122 people (28% believe they don't use enough that it's a problem. Only 5% reported seeking help in the past 6 months. Further clarification is needed to learn what medications and substances are being taken.
- 42% of respondents reported high levels of health literacy with their insurance plans and requirements.

Significant environmental factors

- 22% of respondents had no education, grade school level or some high school. Spanish-speaking Latinos reported educated levels as follows: (26) at grade school level, (10) some high school level, and (3) no education at all.
- 39% respondents reported employment as source of income; but survey respondents with federal or state support totaled 47%
- 47% respondents reported being unaware of the Nassau-Suffolk HIV Health Services Planning Council.

Top 10 reported changes respondents would like to see to improve services for PLWHA:

- 10%- Improved access to Housing
- 8% HIV Education for all
- 6% Better communication of available services; improvements in transportation (Not clear if they were referring to public transportation, or medical transportation that is provided)l money/financial assistance
- 5% Support groups for PLWHA
- 4% Find a cure; free medication
- 3% information on the newest medication and treatment options; Compassion, love and understanding.

The 2019 Nassau-Suffolk Consumer Needs Assessment is a valuable tool to determine how best to meet the needs of our consumers as well as share information and resources.

VII. Administrative Mechanism Report

In the interest of time, the Administrative Mechanism Report was tabled.

VIII. Update on Integrated Plan

The Integrated HIV Prevention and Care Plan is a 5 year plan based upon the NYS ETE Blueprint. It replaces the previous 3 year Comprehensive Service Plan. A statewide document, covering NYC, Long Island, and the upstate and downstate regions, the Plan addresses both HIV Care *and* prevention as joint issues, and is a comprehensive document meant to address the urban, suburban and rural issues of New York State. It is important to note that many of those issues are unique to specific geographic areas, as not all jurisdictions share the same issues and resources.

Data was collected throughout the state for the creation of this plan. The Integrated Plan was drafted and reviewed by various planning bodies before being finalized and approved as a working document. The SAP committee was integral in the development of the Plan and it was shared and reviewed by the Planning Council.

Most recently, in October 2019, the AIDS Institute reassembled the HIV Planning Bodies workgroups as a follow-up of how well the Plan is working in each of the jurisdictions it addresses. The plan received mixed reviews at that meeting:

- Some question the value of the plan, citing redundancy in the Blueprint for ending the epidemic on a statewide basis.

- Its relevancy has also been questioned, since funding streams for HIV Care and HIV Prevention remain separated.
- Some have questioned whether the plan favors regions of the state that are better funded and thereby better equipped to handle the objectives of the blueprint.
- Many generally agreed that the 3 year Comprehensive Service plan made it easier to rate performance in a geographic region, and that it is more difficult to use the statewide 5 year Integrated Plan as working, living document.
- Lack of data, both missing and real-time is proving to be an obstacle.
- On a positive note however, the Integrated Plan is credited for its ability to look at HIV on a broad scale, and for each region to evaluate itself against a broader statewide and national agenda.

The HIV Planning Bodies Workgroup is scheduled to meet again, after the first of the new year, with the intention of moving this conversation forward and to specifically evaluate the effectiveness of the Integrated HIV Prevention and Care Plan.

IX. Other Business/Announcements.

Ms. Alston informed the Council that the target date for CAREWare 6 is November 15, 2019. CAREWare 6 varies from CAREWare 5. There was a request for training on its update.

IX. Adjournment

A motion was made by Ms. Martens and seconded by Mr. Doepper to adjourn the November 13, 2019 Planning Council meeting.

25 Approved 0 Abstentions 0 Opposed - Motion carried.