

Nassau-Suffolk HIV Health Services Planning Council
STRATEGIC ASSESSMENT & PLANNING COMMITTEE
UNITED WAY OF LONG ISLAND, DEER PARK, NY

November 6, 2019

Members Present

Victoria Osk, Esq Co-Chair
Angie Partap, Co-Chair
Ilvan Arroyo
James Colson
Clara Crawford
William Doepper
Kevin McHugh
Joseph Pirone
Jacqueline Ponce-Rivera
Felix Ruiz
Katelin Thomas

Members Absent

Arthur Brown
Lisa Benz-Scott, PhD
Eileen Bryant
Margret Henry
Barbara Martens
June Tappan

Guests

Staff

Georgette Beal
JoAnn Henn
Victoria White
Myra Alston
Katie Ramirez
Stephanie Moreau

I. Welcome and Introductions

Ms. Partap, Chair, opened the meeting at 10:10 am. Introductions were made, followed by a moment of silence to remember those whom we have lost and those that are still here.

II. Final Results of Consumer Survey

Ms. Ramirez presented a Power Point on the results of the 2019 Consumer Needs Assessment Survey. This was the first year the survey was conducted without a consultant. The overall goal was 500 participants. A total of 481 surveys were collected of which 467 were viable responses. Participants were able to complete the survey online through Survey Monkey, in person at Ryan White provider locations, and by telephone. The survey was offered in both English and Spanish. Training was provided to peers who were enlisted to assist with the survey administration. Thanks were extended to the Part A funded agencies, all of which participated, in addition to the peers who worked extremely hard to ensure that their fellow consumers participated this year. Their efforts made it possible to engage a larger audience.

The PowerPoint included a comparison of survey results to the 2017 EPI data in the following categories: Sex at birth, Race/ethnicity, age group and risk category.

Summary of the survey findings:

Race/ethnicity- The breakdown of survey respondents is as follows:

White/Caucasian 39%, Black/African American 35%, Hispanic/Latino 28%, multi-racial 10% and Asian/Pacific and Native American both at 2%.

Age group (years)- The largest number of respondents for HIV diagnosis, were in the 20-29 age range, followed by 30-39, 50-59, and 40-49. For AIDS diagnosis, the age range of 30-39 had the highest number of respondents, followed by 50-59. The 20-29 and 40-49 age bands had the same number of respondents. In addition, there was a comparison between 2019 and 2014 survey results. In the 2019 survey, there was a decrease in the 20-29, 40-49 and 50-59 age ranges. The 60-69 increased by 10% and is now 25%; 70+ increased to 4%, up by 3%. This supports data that shows the individuals are living longer with the disease.

Risk category- In both HIV and AIDS diagnosis, MSM was the largest risk category, followed by heterosexual, and risk not reported or identified. Transmission mode MSM continues to be largest risk category, an increased 9% since the 2014 survey. Heterosexual is next and the percentage decreased by 8%. Perinatal remains constant at 3%.

As stated earlier, there were significantly more male survey respondents. Male was the sex assigned at birth for the majority of responses, which mirrors the EPI data.

5 (1%) responded transgender, male to female, there were no responses of transgender-male to female, 7 (1%) chose not to answer the question. Responses are self-reported.

Income levels-The majority of respondents (21%) reported a monthly income of \$1,000-\$1,499; 16% reported a monthly income of \$750-\$999, as well as \$3,000 or more. It is not clear how much more than \$3,000 was the individual income. One reason why the income is higher than in previous surveys may attributed to more consumers in the workforce either because of better health or more certified peers have gainful employment. Thirty-nine percent (39%) reported employment as their source of income, but survey respondents with federal or state supported income totaled 47%.

Housing Status- There is a need for available and affordable housing options for PLWHA. Seven percent (7%) reported their housing status as currently homeless. Some findings include: the percentage of individuals who are living with their parents or are homeless (either on the streets or at a shelter) has increased significantly. The percentage (12%) of those renting a room in 2019 fluctuated. It increased from 2007 but is down by more than 5% since 2014. Housing issues and concern were voiced during the 2019 community forums as well.

Newly Diagnosed Summary: A total of 36 respondents were newly diagnosed.

- **26** diagnosed in 2018; **10** diagnosed in 2019, **24** males and **12** females
- Race Ethnicity-44% Black/African American, 22% White, 14% multiracial, 3% Native American and Asian/Pacific Islander, 14% other (Hispanic Latino made up 11% of the 14% other)
- Transmission- 47% Heterosexual, 36% MSM, 6% transfusion, 3% MSM/IDU, Other and Unknown

Consumers are living longer, resulting in comorbidities. Of the top 10 reported comorbidities,

High cholesterol (37%), high blood pressure (36%), lung problems, problems with thought or memory, and thrush were all reported at (20%). When asked why cancer, heart and kidney problems were not listed in the top 10, Ms. Ramirez replied that those comorbidities were reported but at 11% and 12% they were ranked lower than the top 10.

Medical Adherence- across all age ranges, the vast majority are currently taking HIV medications. Reasons for non-adherence included undesirable side effects and being too costly, 6 respondents did not elaborate on their non-adherence.

The top 5 services reported as *needed but couldn't get* were divided into medically related and non-medically related. Dental services headed the list. It should be noted at the time of this survey, there were no Part A OHC providers in Nassau County. (A provider has since then been funded.) The other needs were eye care, home health services, mental health/emotional counseling service and medical case management. Non-medically related services reported were in ranked order: assistance to pay for mortgage or rent, money for utilities, assistance with copayments, food bank, and help with finding and keeping housing. Interestingly, three of those services are housing issues.

Respondents are likely to disclose/discuss mental health issues with 50% reporting feeling anxious, depressed or feel that they may have a mental health issue.

Continued reluctance to seek treatment for substance use or even to acknowledge the need for treatment. 122 people (28% believe they don't use to consider it a problem.

Forty-seven percent (47%) of respondents reported being unaware of where to obtain needed services. Only 6% reported being unaware of the Nassau-Suffolk HIV Health Services Planning Council.

The results and findings of the 2019 Consumer Needs Assessment provide valuable insight and necessary information.

III. Integrated HIV Care and Prevention Plan Update

The update began with familiarizing ourselves once again with the Integrated Plan. The portion of the plan outlining the four goals, objectives and strategies was made available to the committee for review. The four goals of the plan are: 1. Reducing new HIV infections and linking newly diagnosed PLWDHI to care; 2. Increasing access to care and improving health outcomes for people with HIV; 3. Reducing HIV-related disparities and health inequities; and 4. Achieving a more coordinated response to the HIV epidemic.

Mr. Pirone recounted and summarized the October meeting of the HIV Planning Bodies Workgroup regarding the plan. The plan is a Statewide document that was created in 2015. Contributors include the NYS Planning Bodies Workgroup, AIDS Institute, UWLI staff and SAP Committee. It is a 5 year plan, founded on the principles of the NYS Ending the Epidemic Blueprint. It address both HIV Care and prevention as joint issues. It covers the areas of NYC, Long Island, upstate and downstate regions of New York State, addressing urban, suburban, and rural issues. While some of the issues are similar, there are problems unique to specific geographical areas. Data was collected and shared. The October meeting was to address how well the Plan is working in each of the jurisdictions it addressed.

Mr. Pirone informed the committee that the plan is getting mixed reviews. Concerns included the possible redundancy of the plan with the ETE Blueprint, its relevancy, since most funding streams for HIV care and prevention remain separated, and the wisdom of evaluating a five year plan since the statewide 5 year is more difficult to use as a working, living document. The question was raised as to whether the Plan favors the regions of the state that have a consolidated geographic area and are better funded and thereby better equipped to handle the priorities of the Blueprint.

However, the Plan is given credit 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 year, moving this conversation forward to evaluate the effectiveness of the Plan. Both Mr. Ruiz and Ms. Shelton attended this meeting.

IV. Overview of FY2020-2021 EIIHA Plan

In the interest of time, the overview of the FY2020-2021 EIIHA Plan will be tabled until the January meeting.

V. Announcements/Adjournment

There were no announcements.

A motion was made by Mr. McHugh and seconded by Mr. Doepper to adjourn the November 6, 2019 Strategic Assessment and Planning meeting.

All in favor-Motion carried.