



## **CONSUMERS COMMITTEE**

Tuesday, January 21, 2020 1:00PM – 3:10PM  
LGBT Center, 208 West 13th Street, NY, NY

### **MINUTES**

**Planning Council Members Present:** Randall Bruce (Co-Chair), Lisa Best (Co-Chair), Atif Abdul-Haqq, Paul Carr, Billy Fields, Charmaine Graham, Ron Joyner, David Martin, Michael Rifkin, Leo Ruiz, John Schoepp, Rob Walker (by phone)

**Committee Members Absent:** Asia Betancourt, Maria Diaz, Jesus Maldonado

**NYCDOHMH:** Melanie Lawrence, José Colón-Berdecía, Graham Harriman, Cristina Rodriguez-Hart, Kimbirly Mack

#### **Agenda Item #1: WELCOME/INTRODUCTIONS**

*Lisa and Randall*, Consumers Committee Co-Chairs, opened the meeting, followed by introductions and a moment of silence. The December 17, 2019 minutes were approved with no changes.

Melanie encouraged members to review the new website and let staff know if there are items that should be posted and areas that need to be cleaned up.

*Paul* gave an update on the Council's other committees' work. PSRA approved the FY 2020 spending scenario, which will be presented for a vote at the January Council meeting. PSRA plans for a possible reduction of up to about 3% to the grant award (the average cut over the last few years has been about 1.5%). The State has said that they can take a cut to the ADAP allocation to offset a reduction to the award. Also, some funds were allocated to pay for the new category of Psycho-social Support for TIGNBNC. In FY 2020, \$50,000 will be used for a resource guide and training curriculum. Starting in FY 2021, \$847,000 will be allocated for two programs to deliver direct services. PSRA will next start looking at areas in the portfolio where allocations can be adjusted to reflect changing needs.

#### **Agenda Item #2: 2020 Consumers Committee Priorities**

*Melanie* presented on the results of the poll of committee members of potential priorities for 2020. The top three ranked priorities were: 1) HIV and Aging, 2) Emergency Financial Assistance, and 3) Policy Changes that will affect HIV Services. A summary of the discussion follows:

- It could have been more helpful to rank all the items, not just the top three.
- Some of the topics overlap.
- Any small groups that meet apart from the full Committee should be open to all members. The chairs should be in the loop and the staff liaison informed so they can send out a notice to everyone.
- It can also be helpful for people to have discussions on their own in between meetings and bring those discussions to the full Committee.

### **Agenda Item #3: HIV and Aging**

*Graham* presented on issues around HIV and aging, with a focus on trends in aging with HIV in NY; identifying the most pressing needs faced by Older People Living with HIV (OPLWH) in NY; ways to meet these needs; and learning about NYC DOHMH's first steps towards creating a better system of care for OPLWH. In 2018, there were 382 new HIV diagnoses among New Yorkers ages 50+ years (121 or 32% concurrent with an AIDS diagnosis), 453 new AIDS diagnoses and 1,332 deaths among OPLWH. Between 2014 and 2018, the proportion of new HIV diagnoses among people ages 50 years and older remained consistent among most transmission risk categories. The number of new HIV diagnoses among people 50 years and older overall declined between 2014 and 2018. However, men over 50 years have had an increase in new HIV diagnoses since 2016. In 2018, Black people 50 years and over had more new HIV diagnoses than any other race/ethnicity. Across nearly all race/ethnicities, the largest proportion of newly diagnosed people were in the 50 to 59 years age group. The proportion of concurrent HIV/AIDS diagnoses was higher among Blacks, Latinos and females. Of the approximately 50,000 people ages 50 years and over with HIV and living in NYC in 2018, 80% had a suppressed viral load. In 2017, 74% of deaths among people 50 years and older with HIV were due to non-HIV-related causes. Among these, top causes were cardiovascular diseases (36%), non-HIV-related cancers, and accidents (11%). Death rates among Black PWH ages 50 years and older were higher than the rates for PWH 50 years and older of other race/ethnicities.

In the NY EMA, the majority of our Ryan White Part A (RWPA) clients are 50 years and older (53.5%) and, when combined with those RWPA participants under the age of 50, represent over  $\frac{1}{4}$  of the total number of PLWH in NYC. The majority of RWPA participants are Black and Hispanic males. More OPLWH are insured than uninsured, indicating insurance status is not a barrier to care and treatment. However, nearly a quarter of RWPA participants over the age of 50 were considered homeless/unstably housed. Over  $\frac{3}{4}$  Lived at or below the federal poverty level.

In 2017, a survey of providers was conducted by DOHMH to better understand the healthcare needs of OPLWH from the provider perspective. 70 responses were gathered from hospitals, clinics, CBOs, government agencies, etc. Questions explored: Resources currently available to OPLWH; Barriers and challenges commonly faced by OPLWH; Areas of unmet service need; and Common resources and referrals provided to OPLWH. The survey reported that the greatest challenges faced by OPLWH in NYC are (in ranked order): Isolation, Stigma, Mental Health, and Housing. Over 80% of respondents indicated that exercise and fitness needs were either unmet or somewhat met. When looking solely at Viral load suppression, it looks like OPLWH are doing pretty well, however, when we asked providers about the overall health and wellness of this population, other areas of need were

identified. Just looking at VLS is not enough, and in doing so, we're missing the larger picture, which includes the social, mental, and physical well-being of the individual.

On January 11, 2018, more than 150 physicians, consumers, service providers and government officials joined the DOHMH to discuss the unique needs and opportunities presented by New York City's aging population of adults living with HIV and AIDS. The event was both education and action-oriented, culminating in an afternoon of brain storming and planning intended to inform efforts to better address the needs of older persons living with HIV (OPLWH). Several key themes emerged from activities held at Community Forum, including: 1) Addressing Social Isolation and those at increased risk of experiencing isolation; 2) Social determinants of health; and 3) Increased need for consumer input (mention to transition to focus groups). There were takeaways on the need for more prevention among older adults, clinical tools to address the whole individual, the need to address more than medical needs, more research needed, and addressing social isolation.

There is a NYC HIV & Aging Focus Group Project, which aims to learn about unmet needs and barriers experienced by OPLHW in the areas of medical care, mental health, social support and other areas. Seven focus groups with 62 participants have been conducted covering all racial/ethnic groups, genders, and boroughs. The average number of years diagnosed among participants was 24 and 90% had public insurance (e.g., Medicaid). Next steps include: in-depth qualitative focus group data, service changes to address social isolation, more client-focused events (e.g., Long-term Survivors Day), increased coordination between State- and City-funded programs, and development of benefits navigation training for clinicians and case managers. DOHMH is currently developing an all-encompassing resource guide and training for clinical and non-clinical providers working with OPLWH in NYC. Training should be available by summer 2020. A summary of the discussion follows:

- Consumers don't always know where to find a resource directory. The service locator map on the website shows how spread out and relatively few services are in Tri-County.
- A booklet can quickly become out of date.
- Evening and weekend services are needed.
- Some insurance companies are lowering the age for reimbursing for gyms memberships.
- Getting people, especially men, to access mental health help is a challenge.
- AA has an app that shows people where the nearest meeting is. Something similar can be used for HIV support. The most effective way to do that would be through a contractor outside the City's IT system.
- A resource guide should take into account whether or not a provider is culturally competent. A draft of the guide can be brought to the Committee for input.
- There's a need for affordable burial insurance.

#### **Agenda Item #4: Consumer Perspectives on What Makes Data Accessible**

Cristina led a discussion with the Committee on how to make data more accessible. Members were given some time to read through the surveillance slides from Graham's presentation or the 2017 surveillance report and shared which slides were easy to

understand and which need more thorough explanation. A summary of the discussion follows:

- The chart in the surveillance report that shows percentages and rates can be clearer (e.g., that the percentage in a column refers to the total in that column, not row).
- Detailed charts with have extensive numbers need explanation. A glossary with definitions (e.g., “row percentage”, “incidence”) would be helpful.
- Narrative explanations that describe the data in a graph or chart will help people understand it.
- A video tutorial on reading this data would be helpful.
- Explain better what “unknown” means. (Unknown often means missing data, but a footnote would help clarify that.)
- Visual clarity can be improved (e.g. headers need to be aligned precisely so that it’s easier to read).
- Bar graphs are visually easier to grasp than line graphs (although line graphs allow data over time to be seen).

*Cristina* thanked the Committee for their input, saying that she will take the comments back to the epi unit.

There was a consensus that the next meeting, the Committee will discuss how to proceed on addressing the topic of HIV & Aging.

*Lisa* also suggested having a review of the Council’s Bylaws so that everyone is on the same page about the role of the committees, chairs, etc.

#### **Agenda Item #5: New Business/Public Comment**

*Paul* reported that City Council Speaker Corey Johnson’s staff has expressed an interest in attending the Committee.

*Paul* made a motion to make the meetings three hours. *David* noted that if people are more concise with their comments, the meeting starts on time and a timekeeper keeps the agenda on track, then the business can be completed on time. There was a consensus that the discussion be tabled to the next meeting.

There being no new business, the meeting was adjourned.