



CONSUMERS' COMMITTEE

Tuesday, June 20, 1PM – 3PM

LGBT Center, 208 West 13th Street, Rm 101, NY, NY

Planning Council Members Present: Billy Fields, Co-Chair, Katrina Balovlenkov, Co-Chair (by phone,) Randall Bruce (Consumer-At-Large), Atif Abdul-Haqq, Paul Carr, Maria Diaz (Co-Chair, TCSC), Saul Reyes, John Schoepp,

Planning Council Members Absent: Lisa Best, Kim Watson

Appointed Community Members: Mark Brown, Ron Joyner

Guests: Daniel Tietz (NYS DOH AIDS Institute), Lawrence Francis, Gordon Moore, Maurice MP White

NYCDOHMH: Jose Colon-Berdecia, Melanie Lawrence, Darryl Wong

MEETING MATERIALS DISTRIBUTED:

- Meeting Agenda;
- Ground Rules for Respectful Engagement;
- May 16, 2017 Meeting Minutes;
- The Living Cascade, Powerpoint presentation, Daniel Tietz, NYSDOH AIDS Institute, 7/17;
- The Living Cascade Worksheet (Draft), Dan Bellanger, NYSDOH AIDS Institute, 7/17;
- NYS Cascade of HIV Care, 2015 and Cascade of HIV Care, 2015 comparison, NYSDOH;
- NY HIV Planning Council Monthly Outreach Report, May 2017;
- NY HIV Planning Council Consumers Committee Outreach Venue Suggestion Sheet;
- July 2017 Borough Ending the Epidemic (ETE) Meeting schedule;
- NY HIV Planning Council June & July 2017 calendars;
- Consumers' Committee May 2017 Meeting Evaluation Results; and
- Consumers' Committee June 2017 Meeting Evaluation (to be completed).

WELCOME/INTRODUCTIONS/REVIEW OF MINUTES

Darryl Wong, HIV Planning Council Deputy Director and Consumers Committee Staff Liaison opened the meeting awaiting the arrival of Co-Chair *Billy Fields*, with Co-Chair *Katrina Balovlenkov* participating by telephone. After member introductions, *John Schoepp* led the group in a moment of silence in honor of those who have been lost and those who continue to struggle with HIV/AIDS. The meeting agenda and materials were reviewed and the May 2017 meeting minutes were accepted as presented.

PUBLIC COMMENT

There was no public comment.

THE LIVING CASCADE/QUALITY IMPROVEMENT

Daniel Tietz, Manager of Consumer Affairs at the NYS Department of Health AIDS Institute presented an overview of The Living Cascade, explaining its purpose, how to build a "living" cascade focusing on the patient experience, how to interpret the cascade and setting goals (personal or facility-specific) based on the cascade.

The purpose of the cascade is to show the number of individuals living with HIV infection, the medical care they are receiving, the medical care they need, and the results of that care. It can be utilized as a visual tool of HIV care and outcomes at a point in time to 1) monitor the extent and quality of care being delivered to all HIV-positive patients (either personal experience or seen at an organization) 2) assess key parameters of care for persons living with HIV 3) identify gaps in care 4) prompt discussion on steps to improve HIV care outcomes and 5) create data-driven plans to assess and improve care through QI activities.

Of 1.1 million Americans living with HIV, only 25% are virally suppressed (CDC, 2012).

The "cascade" is a population-based tool that has been adapted by agencies to show their HIV care outcomes. The components of an effective cascade should be accurate, consistent, understandable, focused on the target audience and be adapted for usage with QI activities.

Questions to consider when using/examining the cascade include: 1) if you improve the steps along the continuum, will there be an increased chance that patients will achieve better sustained health outcomes? 2) with each process step along the cascade involving a human interaction, all of the steps together are a journey the consumer takes. Working together, can we improve the consumer journey and help the consumer to arrive at a place of sustained health? 3) How can we partner with the provider community beyond our clinic walls to improve outcomes along the treatment cascade?

It is important to remember and acknowledge that each step/process along the continuum involves a human interaction and the data are composed of real clients. With the goal of understanding how a quality improvement approach to service receipt/provision can help PLWHAs to become engaged in care and to stay healthy, we can qualitatively document the consumer cascade journey from an open case status, to an active case status, to use of ARTs resulting in viral suppression and finally undetectability (currently less than 20 copies of viral RNA). By improving supportive processes to successfully move PLWHAs along the continuum of care and helping consumers to become virally suppressed and maintain health, consumers of HIV care can play a central role in ending the epidemic by 2020.

POWER OF QUALITY IMPROVEMENT CONFERENCE – NOVEMBER 2017

Mr. Wong introduced *Jennifer Carmona*, Director of Quality Improvement at the NYCDOHMH Bureau of HIV/AIDS, who provided the overall organizational context for the Consumers' Committee participation in the Power of Quality Improvement conference, slated for November 2017. The full-day conference will be held in November at the Kimmel Center at New York University and will be free of charge with breakfast and lunch provided. She announced that a call for abstracts will be released sometime in July/August with a September deadline and that there will be a specific session addressing consumer engagement in quality improvement from a consumer-centric perspective in the afternoon. In addition to the more traditional panel discussions, there is latitude to develop interactive presentations and activities which will showcase consumers' lived experiences as PLWHAs.

The Living Cascade (see above for background) was introduced to the Committee as a possible vehicle to elicit qualitative input related to consumers'/patients' experiences along the HIV Care Continuum/Cascade in order to identify and make recommendations aimed at improving HIV engagement, care and treatment outcomes from a client-centric perspective. It is envisioned that individual Planning Council Consumers Committee members would complete the tool, which allows for open-ended responses to questions on consumers' perceptions, experiences and motivations from initial diagnosis through viral suppression. Responses would be analyzed for common themes, root causes, drivers, motivations, reactions and approaches to various stages of the Living Cascade.

Mr. Wong then reviewed the committee's *Community Advisory Board (CAB) Survey Project*, completed in 2012. This cross-sectional study was developed to capture operational aspects of each Part A funded

CAB including barriers to participation and best practices for CAB recruitment, engagement, input and feedback processes. It was presented to the Committee for consideration

The third option that was presented was the *Consumer/Provider Role Play* exercise, which can enable consumers to identify the communication issues and barriers that have prevented/hindered them from moving successfully through the continuum, from initial diagnosis through viral suppression. This is designed to be a dynamic interaction highlighting the communication, interpersonal or informational barriers that emerge in the dialogue between consumers/providers, with a view towards developing consumers' skills to be self-advocates by developing an action plan to solve/address issues identified as challenging.

Saul Reyes made an impassioned plea to Committee members to think "outside the box" and to generate ideas for presentations that reflect consumers' priorities, not just the priorities of the DOHMH, the Grantee or the Planning Council. *Mr. Tietz* offered the resources of the National Quality Center and the entire set of NYSDOH AIDS Institute resources on Consumer Engagement to the committee for their use in identifying and honing in on systemic approaches that promote QI from a consumer's lens. *Mr. Fields* and *Jan Park* urged the committee to focus on the opportunity for consumers to organize and develop the presentation(s) of their choosing. It was suggested that a member contact list be updated and circulated so that members may communicate among themselves. There was agreement that a subcommittee should be convened in July, before the regular monthly meeting on July 18, in order to organize the structure of the Subcommittee and to establish a schedule moving forward.

PLANNING COUNCIL COMMUNITY OUTREACH ACTIVITIES: MAY 2017

Jose Colon-Berdecia, Planning Council Community Outreach Coordinator, presented the Monthly Outreach Report for May 2017, noting that eleven (11) Planning Council outreach presentations were conducted in Staten Island, Manhattan, Queens and the Bronx. *Mr. Colon-Berdecia* asked each committee member to recruit one person from each organization/network with which they are affiliated or seek care. Members were asked to also please share community advisory board (CAB) affiliations and contacts, if possible. An outreach venue/contact referral sheet was distributed to all meeting participants, who are asked to refer potential outreach sites/individuals directly to *Mr. Colon-Berdecia* for initial contact and follow-up.

CONSUMERS COMMITTEE OUTREACH BROCHURE RE-DESIGN

Mr. Wong informed the committee that the Bureau of Communications has declined our request to have an ADA symbol included in the brochure. It was suggested that we develop some language for the brochure speaking to accommodations that are available for persons with mobility and hearing impairments.

OTHER PLANNING COUNCIL UPDATES

Mr. Park reported that we have received our Notice of Award, representing a 1.87% cut from last year.

PUBLIC COMMENT/NEW BUSINESS/ADJOURNMENT

Paul Carr offered GMHC's space for subcommittee meetings. *Lawrence Francis* announced that 1) the Upper Manhattan ETE Task Force will take place on July 5 from 1-3PM at FACES/NY and 2) FACES will have a float at the Pride March on June 25. *Billy Fields* circulated information on an all day ACT UP conference on May 21.

There being no further business, the meeting was adjourned at 3:30 pm.

