



CONSUMERS COMMITTEE

Thursday, May 21, 2014, 2:00 – 4:30 PM

NYCDOHMH, 42-09 28th Street, Room 16-49, Long Island City, NY

Planning Council Members Present: David Martin (Co-Chair), Billy Fields (Co-Chair), Randall Bruce (Consumer At Large), Deborah Marcano, Pastor Jerome Payne,

Planning Council Members Absent: Victor Alvarez (Tri-County), Lotus Blackman, Felicia Carroll, Kareem Clemons, Rev. Keith Holder, Muying Hunt, Antonio Munoz, Tracy Neil, Saul Reyes

Appointed Community Members: Jose Colon-Berdecia, Ron Joyner, Joey Lopez, Glen Phillip

NYCDOHMH: Rafael Molina, Darryl Wong

MEETING MATERIALS DISTRIBUTED:

- Meeting Agenda/Planning Council Ground Rules of Respectful Engagement;
- March 19 & April 16, 2014 Meeting Minutes;
- 2013 Consumer Listening Sessions – Treatment Cascade, Summary Report & Powerpoint of Key Findings, NYCDOHMH/CAI;
- AIDS Watch – Ending AIDS in America, May 2014;
- Consumer Committee March 2014 Meeting Evaluation;
- Consumer Committee April 2014 Meeting Evaluation;
- The HIV Care Continuum, www.aids.gov, May 2014;
- The Care Continuum in NYC in 2012 by Borough of Residence, NYCDOHMH, May 2014;
- Policy Committee Letters to Mayor DeBlasio re: SEPs, Mail Order Pharmacies, May 2014;
- Advocating Pill, US Signals Shift to Prevent AIDS, NY Times, May 14, 2014;
- NYCDOHMH HIV Planning Council Grantee Report, May 2014;
- FY14 HRSA Notice of Award, 4/25/14;
- Speak Out Youth Ambassadors Application;
- NYC Resources for LGBTQ Teens, Spring 2014;
- NYCDOHMH 2014 Heat Advisory, May 2014;
- POZ Magazine, June 2014;
- May 2014 & June 2014 HIV Planning Council Meeting Calendar;

WELCOME & INTRODUCTIONS/PLANNING COUNCIL UPDATES

David Martin and Billy Fields, Co-Chairs of the Committee opened the meeting, followed by a moment of silence led by Pastor Payne and member and guest introductions. The Rules of Respectful Engagement, the meeting agenda and materials were reviewed. The minutes from the March 19 and April 16 meetings were accepted as presented.

The April meeting evaluation results were distributed, noting that meeting start/end times, agenda structure and meeting location remained challenging for some participants. There was significant positive feedback on the inclusion of transgender issues in our discussion.

The NYCDOHMH, as grantee, received notification from HRSA on the FY14 award, which includes an increase of \$1.2 million in additional funds, as well as receipt of the core medical services waiver, which allows the grantee to allocate less than 75% of funds to direct services, with the remaining funds to be used for non-core support services.

It was announced that the Planning Council is currently recruiting new members for the next cycle. Applications are available through www.nyhiv.org.

PUBLIC COMMENT:

It was suggested that when addressing HIV in faith-based communities, issues be framed more holistically around health and strategies to become/remain healthy.

REVIEW OF NATIONAL, NEW YORK STATE & NEW YORK CITY HIV CARE CONTINUUM/TREATMENT CASCADES

The HIV care continuum, also referred to as the treatment cascade, is used nationally and locally to identify issues and opportunities related to improving the delivery of services to PLWHAs across the continuum of care. This continuum has (5) main steps, or stages: (1) HIV diagnosis, (2) Linkage to care, (3) Retention/Staying in care, (4) Receiving anti-retroviral therapy and (5) Achieving viral suppression. The national care continuum shows that there are significant drop-offs at each stage, with 20% of those infected with HIV (estimated at 1.1 million people) being undiagnosed. The latest CDC data shows that only 25% of PLWHAs in the US have achieved viral suppression, i.e., 75% of those infected do not have their virus under control.

Statewide, in 2012, 44% of those who are diagnosed with HIV have achieved viral suppression. In New York City, 41% of individuals have suppressed viral load; a borough by borough analysis shows that rates of viral suppression range from 40% (Staten Island) - 43% (Manhattan & the Bronx).

2013 LISTENING SESSIONS – SUMMARY REPORT OF KEY FINDINGS

A total of six (6) listening sessions were held in the five NYC boroughs, as well as Westchester County (the Tri-County region) between May and June 2013. Five sessions were conducted in English, and one session was conducted in Spanish. Themes were presented as the most common responses to questions related to barriers and facilitators to accessing HIV testing and treatment services, along the treatment cascade/HIV care continuum, as described above. Listening session participants were also asked to describe an ideal system of HIV care.

Barriers to HIV Testing: Lacking knowledge of HIV risks; sense of invulnerability; not wanting to know status; concerns regarding discretion and confidentiality; stigma of HIV and lack of social support and lack of knowledge of where to get tested and what services are offered.

Facilitators to Testing: More education outreach in multiple languages and greater utilization of peers for pre-post test counseling.

Barriers to accessing treatment services: Concerns regarding confidentiality; inconvenient clinic hours and wait times; inconvenient clinic location and lack of transportation; poor provider-consumer relationship and the lack of bi-lingual staff at clinics.

Facilitators to accessing HIV treatment services: Greater assurance for consumers regarding their rights to confidential care; caring providers; having the support of a peer mentor improvement/oversight of transportation system; extended clinic hours; and more bilingual staff at clinics.

Barriers to initiating ART: Depression & isolation; fear of side effects; widespread misconceptions about medications; and being in denial about HIV progression.

Facilitators to initiating ART: Greater education and communication regarding side effects; consumers feeling empowered to have input into their healthcare decisions; and good provider-consumer communication.

Barriers to maintain viral suppression: Poorly coordinated system of HIV care; feeling better and stopping treatment; having poor communication with providers; having competing responsibilities; not disclosing status; and living in poverty/ being transient.

Facilitators to maintaining viral suppression: Developing integrated team of providers, with peers as integrated team members; automated reminders to take medication; caring providers; continued education of consumers on importance of being adherent; and greater integration of HIV care with other social support services, especially housing.

Characteristics of an ideal system of HIV care: Better integration of HIV care with other social services, such as housing, food security and mental health services; improved transportation services; wider availability of specialists in all boroughs and upstate – especially for provision of mental health services; provision of bilinguals services for both HIV education/outreach and care; engaging family/significant others in managing HIV; focus on advocacy; and system is developed with input from consumers and HIV care providers.

ADJOURNMENT:

There being no further business, the meeting was adjourned at 4:15PM.