



CONSUMERS COMMITTEE

Wednesday, December 15, 2010 1:00 – 3:00PM
LGBT Center, 208 West 13th Street, Room 410, New York, NY

Planning Council Members Present: John A. Eddie (Co-Chair), Kareem Clemons, Yves Gebhardt (for E. Viera, Jr.), Munying Hunt-Chena, Alexander Hardman, Keith Kaiman

Planning Council Members Absent: Victor Benadava (Co-Chair), Brent Backofen, Felicia Carroll, Gerald DeYounge, Steve Hemraj, Hilda Mateo, Pastor Jerome Payne

Community Members Present: Randall Bruce, Gregory Cruz (Consumer At-Large), Stewart Fogel, Delores Henley, Mallory Marcus, Marit Nagy, Joseph Ogun, Glen Phillip, Manuel Rivera, Joseph Sellman

DOHMH: Jan Carl Park, Heidi Gortakowski, Ellen Weiss Wiewel, Terri Wilder, Darryl Wong

MEETING MATERIALS DISTRIBUTED:

- Meeting Agenda;
- Planning Council Ground Rules of Respectful Engagement/Rules for Public Comment;
- November 17, 2010 Draft Meeting Minutes;
- Announcement of death of Randy Allgaier, San Francisco Chronicle, December 2, 2010
- NASTAD ADAP Waiting List Update, December 10, 2010
- Operational Plan for NHAS, HHS Update, 12/9/10
- Moving Forward to Implement the National HIV/AIDS Strategy, HHS Update, 12/10/10
- AIDS Watch 2011 Agenda, NAPWA/TAEP
- CAB Announcements for Staff and Consumer Leaders/Consumer Member Representatives, & Eligibility Screener for Staff Representative, NYCDOHMH, BHIV, CTH Program, Research & Evaluation, December 2010
- NYCDOHMH HIV Self-Management Education Program Description
- HIV Epidemiology in New York City, 12/15/10, HIV Epidemiology & Field Services Program, NYCDOHMH
- Recent Geospatial representations of HIV surveillance data, 11/29/10, NYCDOHMH

INTRODUCTIONS:

In the absence of both Co-Chairs, Darryl Wong from NYCDOHMH welcomed participants. Randall Bruce led the moment of silence was observed and the meeting participants reviewed the Rules of Respectful Engagement and Rules for Public Comment.

Darryl Wong reviewed the meeting agenda and meeting materials, noting that there is a public comment period of (15) minutes scheduled at the end of the meeting to address any issues of concern to Committee participants. A member of the public voiced his concern that the agenda has been developed without input from membership; it was noted that the agenda was developed in concert with both Co-Chairs.

The minutes of the November 17, 2010 meeting were reviewed and approved.

PLANNING COUNCIL UPDATES:

In response to the HRSA Planning Council Assessment, a response plan, including recommendations and action steps was presented with projected deliverables. A comprehensive training plan will developed for Planning Council members, alternates and Committee members; Leadership Training Institute (LTI) and other online trainings will be made available a/o January 2011. It was noted that there will be additional discussion about the chronic care model and its implications. Although the HRSA consultant who conducted the assessment is not currently available to meet with the Planning Council, a request for follow up technical assistance was made; HRSA has proposed a mid-March meeting in NYC.

Mr. Park provided a brief review of December Planning Council activities and committee meetings, including the Executive Committee at which two proposed Bylaws revisions were referred back to the Rules & Membership Committee (RMC) for further discussion. One proposed revision referred to the election procedure of the Consumer At Large; it had been suggested at the December RMC meeting that the representative should be a Mayorally-appointed member of the Planning Council and that this individual be elected jointly by both the PLWHA Advisory Group and the Consumer Committee. It was suggested that in order to assure a more inclusive discussion a notice of the RMC meeting be sent to PLWHA AG and Consumer Committee members.

A Committee member inquired as to the final disposition of CARE network documents and files; it was suggested that he follow up directly with the NYSDOH/AIDS Institute Part B Network coordinators.

Darryl Wong reviewed the scripts developed by Research & Evaluation of NYCDOHMH for the CAB best practices/effectiveness survey. These scripts will be utilized to establish initial contact with CAB agency staff leadership, consumer leaders and consumer members. The survey will be ready to be posted on Survey Monkey. Members were asked to provide written feedback on the scripts

NYCDOHMH HIV SELF-MANAGEMENT EDUCATION PROGRAM:

Terri Wilder, Director of the HIV Self-Management Education program at NYCDOHMH provided an overview of the program, which was funded in the fall of 2010, under the Early Intervention Services (EIS) service category. The goal of the program is to enable HIV-positive participants to gain knowledge, motivation, skills and emotional and practical support to make behavior changes that will improve their health and quality of life. This series of 3 day gatherings (one four hour program followed by a two day program), to be repeated ten times/year will provide peer-led and specialist-led workshops that help ~3,000 PLWHAs, especially those who are newly-diagnosed, to improve their HIV health literacy and become empowered to proactively participate in their health care. Questions from committee members included

- (1) Was feedback solicited from New York State on their patient self-management program?
- (2) Would this program be available to consumers from the Tri-County region?

Ms. Wilder sought feedback from the Committee on the program, focusing on the following questions:

- 1) What resource could help people with HIV manage their own health & stay healthy and what do newly-diagnosed people with HIV most need to help them manage their health?

Responses included:

- o HIV medication adherence and insure access to medication;

- Exercise;
 - Access to proper nutrition and nutritionists;
 - Healthy, stable living environments;
 - Support mechanisms;
 - Child care;
 - Counseling;
 - How to access services, local resources;
 - Establishing a relationship with a medical care provider; and
 - Replicate best practices used by other agencies;
 - Peer mentors & support groups, especially those who are long-term survivors, not on medication.
- 2) What would be a good name for a program that helps people improve their health?
- Maintenance care;
 - A new strategy to life;
 - Staying active;
 - It's not over;
 - Adhere to it;
 - You can do it;
- 3) Given the challenges with client recruitment and retention, what is best way to spread the word about programs and services for people with HIV?
- Outreach – through condom distribution, word of mouth, flyers, subway ads and bus shelters, and
 - Culturally & linguistically sensitive methods of reaching hard to reach populations

HIV/AIDS IN NYC – EPIDEMIOLOGICAL UPDATE

Ellen Wiewel of the HIV Epidemiology & Field Service Program, NYCDOHMH, gave an overview of HIV/AIDS epidemiology in New York City. NYC continues to have the highest prevalence and second highest incidence of HIV infection among major cities in the US. While data shows a steady drop in new infections from 2005 (4,360) to 2009 (3,684), the 2009 data is not complete and the numbers are expected to rise. The number of people living with HIV/AIDS continues to rise and age, with the same pattern of incidence by neighborhood continuing for several years. Death rates are lower in one high incidence neighborhood (Chelsea-Clinton). It was noted that treatment guidelines have changed, with treatment recommended at <500 CD4, rather than 350. Given that treatment and suppressed viral load improves PLWHA health and decreases risk of transmission, it is important to encourage testing, promote timely linkage to HIV medical care and other forms of support after diagnosis, and to offer treatment earlier.

Heidi Gortakowski presented on new ways that the DOHMH HIV Epidemiology and Field Services Program is developing to provide more useful mapping of HIV in the City. Using

population-based surveillance, while maintaining strict confidentiality, density maps can show, within a one-mile radius, concentrations of HIV infection among many populations. For example, the new mapping shows that HIV incidence among black men is significantly higher among black men who do not live in blacks neighborhoods. The mapping was also able to pinpoint a concentration among Latino, foreign-born MSM in western Queens. This kind of data can help tailor prevention and care strategies with more precision.

Highlights of the discussion and question and answer period:

- HIV was not reportable until a State law authorized it in 2000, which is why there is no HIV data from before that.
- Riker's Island is included as part of West Queens for cases that are diagnosed on the island.
- Reasons for the higher death rates could include higher incidence of delayed diagnosis and other co-factors (e.g., incidence of hepatitis C infection among IDUs).
- Having more specific data than UHF data (e.g., by ZIP code) is more useful.
- DOHMH is examining why there is a decline in new diagnoses when there has been a big push to increase testing (this is partly due to the lag in reporting).
- DOHMH is aware that they are undercounting homeless people, since they rely on providers reporting the housing status of their patients. Also, people in shelters are not counted as homeless.

PUBLIC COMMENT:

Manuel Rivera reiterated the need for a discussion on the roles that consumers can play in planning for HIV/AIDS services in NYC. He expressed his concern that the Advisory Group and Consumers Committee will be combined, thereby diluting the voice of independent PWAs.

ADJOURNMENT:

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