



### **Consumers Committee Meeting**

April 15, 2009, 1:30 - 3:30PM

Housing Works, 57 Willoughby Street, Brooklyn, NY

**Members Present:** Victor Benadava (Co-Chair), John A. Eddie (Co-Chair), Brent Backofen, Anthony Case, Felicia Carroll, Gregory Cruz (Consumer At- Large), Gerald DeYounge, Linder Ford, Billy Fields, Yves Gebhardt, Juanita Owens, Glen Phillip, Escott Solomon

**Members Absent:** Terri Faulkner, Myron Gold, Alvin Perry, Marcelo Soares, Edilberto Viera, Jr.

**Guests Present:** Ronald Brown, Renee Bacott, Joseph D. V., Barry Harris, Julian Huiett, Ron Joyner, Mallory Marcus,

**DOHMH:** Rafael Molina, Darryl Wong

#### **Meeting Materials Distributed:**

- April 15, 2009 Meeting Agenda
- Rules for Respectful Engagement
- March 18, 2009 Consumers Committee Meeting Minutes
- March 19, 2009 Planning Council Resolution
- NYCDOHMH response to PC Resolution
- Community Co-Chair March 2009 Testimony
- April 2009 Planning Council calendar
- Food & Nutrition Services Guidance
- DHHS/CDC Announcement of Act Against AIDS, Leadership Initiative
- NAPWA/AIDS Watch & ETHA briefing announcement
- NAPWA/Denver Principles Project
- Patient-Physician Connectedness & Quality of Primary Care, Annals of Internal Medicine, 2009;150:325-335
- “Making Sure Your HIV Care is the Best It Can Be” May 5, 2009 Training Announcement
- HIV Planning Council 2009 Membership Application, due May 18, 2009
- The AIDS Drug Assistance Program: Securing HIV/AIDS Drugs for the Nation’s Poor and Uninsured, March 18, 2009, AIDS Action/AIDS Institute Council

Victor Benadava welcomed participants, followed by introductions. Glen Phillip led the moment of silence in memory of PLWHA, with an acknowledgement of Myron Gold and his health struggles. Mr. Eddie reviewed the Rules of Respectful Engagement and Darryl Wong reviewed the agenda and meeting materials.

The minutes from the March 18, 2009 meeting were reviewed and approved with minor changes in participants’ attendance noted.

#### **HIV Planning Council Update:**

Darryl Wong reported on the following activities:

- AIDS Watch will be convening on April 27-29 in Washington, D.C. where PLWHAs will have the opportunity to talk to their Congressional representatives. Bailey House, Housing Works, GMHC and other ASOs are providing buses for consumers to travel to Washington, D.C. Consumers interested in participating in AIDS Watch were advised to contact Kali Lindsey at NAPWA for travel information.
- Mr. Jeff Crowley has been appointed to the White House Office of National AIDS Policy by President Obama and has a long history in advocacy for PLWHAs, having served as a past Deputy Executive Director of the National Association of People with AIDS (NAPWA), where he developed the National HIV Testing Day initiative and the Positive Youth Conference series. Mr. Crowley is overseeing the development of the National AIDS Strategy, which he has indicated will include PLWHAs in its Working Groups.
- Soraya Elcock spoke at the City Council hearings in opposition of the elimination in Scattered Site II Housing, the reduction in Case Management staff at Supportive Housing programs and the 50% reduction in HASA-funded HIV/nutrition programs.
- The Leadership Training Institute (LTI), supported by Ryan White funds, will no longer be contracted through and overseen by the NYS DOH/AIDS Institute and instead will be contracted through and report directly to NYCDOHMH. In addition, the Understanding Data and the Priority Setting/Resource Allocation trainings will be combined into one training; the other trainings will continue as they have in the past, with the exception of some mini-trainings to be included. These trainings will be targeted to PLWHAs currently or planning to be involved in the Planning Council; prior participants will be able to repeat trainings.
- The PLWHA Advisory Group will be meeting on April 18, 2008, with Anthony Sumpter from HASA and Dr. Laraqe presenting on Women & Girls & HIV/AIDS. Other invited guests are still pending, including Speaker Christine Quinn.
- The Care Coordination RFP Special Task Force will have its initial meeting on Monday, May 4, 2009. This Task Force was created in response to the Planning Council March 19, 2009 resolution (see above). The transcripts from the March & April 2008 Integration of Care and Planning Council meetings will be available, as will other materials distributed in that timeframe. The Care Coordination RFP has been released and is currently “in play” and will not be withdrawn. The discussion will focus on 1) the planning, input and development process of the service guidance/model for Medical Case Management, 2) the respective roles of the Planning Council and the NYCDOHMH and 3) the steps that need to be in place in order to assure that future service guidances/models for service categories to be re-bid are reflective of community/provider input. The second Special Task Force meeting is scheduled for Monday, March 18, 2009. Gregory Cruz clarified that the Integration of Care Committee, last Spring, developed the service guidance for the DOHMH to develop as a model for the RFP, but that the guidance was not reflected in the RFP.
- Felicia Carroll commented that this experience underscores that active and consistent participation in the planning process is vital and that consumers should not be dissuaded from completing the 2009 HIV Planning Council application. Darryl repeated the need to understand conflict of interest guidelines as it applies to the planning process.

**Medical Monitoring Project (MMP) Update:**

Victor Benadava participated in a national conference call with CDC and other local MMP CABs, during which 1) the importance of the national project, 2) patient confidentiality issues for participants and 3) heightened local outreach and recruitment, through primary providers, to increase enrollment in the project were discussed. Data from the initial wave of recruitment (two years ago) is forthcoming.

#### **Consumer Focus Groups Update:**

Darryl reported that approximately 125-130 individuals participated in the March/April 2009 Consumer Focus Groups, which were held at local CBOs throughout the City, with at least one focus group per borough, except for Manhattan, Brooklyn and the Bronx where two groups (males only and females only) were conducted. There were also focus groups targeted to special populations, including younger people, older people, newly-released people from jails, people of transgender experience and Spanish-speaking individuals. The data will be analyzed in April/May and presented to the Planning Council in June for use in the next cycle of care, treatment and housing program planning. Escott Solomon added that outreach to participants who were not part of the planning process was successful and Darryl echoed the observation that many new focus group participants were eager to participate in both the next series of focus groups as well as the planning process.

#### **Denver Principles:**

Darryl provided an historical background to the Denver Principles, which were developed in 1983, at a national health conference, where several AIDS activists convened and drafted the first manifesto on self-empowerment for people living with HIV/AIDS, which details the rights of and recommendations for people with AIDS, health care professionals and for the general public. There was a brief review of the Denver Principles Project, a collaborative between the National Association of People with AIDS (NAPWA) and POZ magazine, which seeks to increase membership in NAPWA, and in so doing, to build the largest national network of PLWHAs and allies possible and giving it the voice and authority it needs to be a powerful advocate.

#### **Integration of Care Committee:**

John A. Eddie reviewed the process of development for the service guidance for the Food & Nutrition Services service category. The Integration of Care Committee began the process of articulating the components of the service category. Victor summarized IOC's input, that food provision and nutrition services should be integrated, as opposed to separate, discreet services, all under the supervision of a registered dietician. The next IOC Committee meeting will be on April 28, where the guidance will integrate members' concerns and input. Darryl underscored the importance of attending IOC meetings in order to fully understand the development of service guidances. Outreach to Homeless Street Youth will be discussed at future Needs Assessment Committee and IOC meetings, where a service guidance and model will be developed.

#### **COMMUNITY UPDATES:**

NYCAHN will be convening a march on Thursday, April 16, beginning at 11AM from South Street Seaport to City Hall.

Bill A.2565/S.2890 (Glick,Duane) needs support to cap expenditures on rent at 30% of monthly income for PLWHAs.

**Community Updates:**

The Consumers Committee of the Manhattan HIV CARE Network will be meeting on Tuesday, April 21 at NYCDOHMH, 158 East 115<sup>th</sup> Street.

NYCAHN will be conducting a training on advocacy on Thursday, March 19.

**Public Comment/New Business:**

There is a need for non-emergency transportation re-imbusement for PLWHAs

**Adjournment:**

There being no further business, the meeting was adjourned at 3:45PM.