



## **HIV Health and Human Services Planning Council of New York**

Meeting of the Consumers Committee

April 16, 2008, 1:30PM – 4:00PM

Housing Works, 57 Willoughby Street, Brooklyn, NY

**Members Present:** Victor Benadava, Felicia Carroll, Orbit Clanton, Gregory Cruz, Manuel Ducret, Billy Fields, Linder Ford, Myron Gold, Juanita Owens, Glen Philip, Anthony Richardson, Marcelo Soares

**Members Absent:** Brent Backofen, Terri Faulkner, Myron Gold, Hilda Mateo, Gonzalo Mercado, Alvin Perry, Glen Phillip, Aracelis Quinones, Escott Solomon, Robert Spellman, Edilberto Viera, Jr.

**Guests Present:** Timothy Benston (NYSAI), Yves Gebhardt, Robert Jones

**DOHMH:** Jan Park, Rafael Molina, Darryl Wong (Consumers Committee Staff Liaison)

### **Meeting Materials Distributed:**

- April 16, 2008 Consumers Committee Meeting Agenda
- April 2008 Planning Council Meeting Calendar
- March 19, 2008 Meeting Minutes
- Consumer Focus Group Guide – IRB Approved
- 2008 Spending Plans – Base & MAI
- Letter in Support of HR 5613 – 1 year Moratorium on Medicaid regulations
- Letter in Support of A 09195 – Routine HIV testing
- Policy Issue Update

### **Welcome and Introductions:**

Felicia Carroll, Co-Chair, welcomed the group and participants introduced themselves. Alvin Perry is ill and unable to attend. Myron Gold led the group with a moment of silence, noting the passings of advocates Helen Hernandez & Vilma Santiago. Glen Philip reviewed the Rules of Respectful Engagement and Darryl Wong, NYCDOHMH, reviewed the agenda for the afternoon's meeting.

### **Review of March 19, 2008 Minutes:**

The minutes from the March 19, 2008 meeting were reviewed. G. Cruz requested that meeting minutes be made available in advance of the meeting so that members have sufficient time for review and approval. J. Park updated the Committee with information regarding the HASA Advisory Board appointment process and noted that Sallie Adams, the HASA representative on the Planning Council will be available at the April 17, 2008 Planning Council to answer questions. A suggestion was made to use email in lieu of hard copies. However, some members do not have access to email. Motion was made to accept the minutes; vote taken, minutes accepted.

### **April 2008 Planning Council Activities:**

Jan Park provided an update of Planning Council Committee activities:

*The Needs Assessment Committee* meeting focused on the CHAIN studies which are undertaken by the Mailman School of Public Health through a subcontract with the grantee. *The Priority Setting/Resource Allocation Committee* met to approve the preliminary 2008 spending plan/budget. Jan Park provided a review of the 2008 spending plan for the NY EMA, noting that \$84.6 MYN is available for base spending

and \$7.5 MYN for the Minority AIDS Initiative (MAI), which serves specifically minority communities in NYC. The concepts of un-committed funds, re-direction of resources, ongoing monitoring of the EMAs spending and non-programmatic expenditures was discussed. Committee members were reminded of their roles, as consumers, in influencing where resources are allocated and which services are funded and were encouraged to attend and participate in as many meetings as possible. *The Policy Committee* will be presenting two letters for the Planning Council's support; the first addresses changes in HIV testing and the second addresses a proposed moratorium on Medicaid regulations and changes that will make cuts to the Medicaid program.

### **PWA Advisory Group Update**

Changes to the structure of the Advisory Group and Sub-Committees are being discussed. At the last Advisory Group meeting, a presentation on transgender HIV/AIDS was given.

### **Update with Dr. Fabienne Laraque**

Dr. Laraque, Director of the Office of Care, Treatment and Housing, shared her vision of increasing access to primary medical care and support services and care coordination. M. Gold reminded members that although HIV may be viewed as a chronic disease, many people are quite sick and PWAs are succumbing. M. Soares noted the absence of a comprehensive Ryan White resource directory, which is currently being updated for the website. Dr. Laraque reviewed the underlying principles of the Maintenance in Care program. The role of Quality Management Initiatives from consumer perspectives was discussed; Tim Benston of the NYS AIDS Institute reminded the Consumers Committee that quality management trainings are being planned for this Spring. A. Richardson and O. Clanton noted that there is a paucity of data on PWAs in NYC who are differently-abled. G. Philip reminded the Committee that Brooklyn is experiencing a decline in the number of providers, despite an increase in new AIDS cases and J. Owens noted the particular challenges of women and families living with AIDS. L. Ford noted the lack of media campaigns for HIV prevention & for PWAs.

### **Follow-up discussion of Consumer Focus Groups**

The first series of Consumer Focus Groups occurred on Thursday, April 10 and Friday, April 11. Positive feedback on the focus groups includes the following remarks:

- There was much agreement among participants on the priorities articulated and service gaps;
- Consumers perceptions were validated by Spending plans;
- The facilitators were well-prepared and organized, their approaches were appropriate and the facilitation was professional;
- Good discussion on under-served populations;
- Discussions were detailed as to the continuum of care behavior – accessing care, staying in care;
- Questions were pointed and logically-ordered, discussions flowed well;
- Focus groups were informative for participants;
- There was the opportunity to discuss the quality of services;
- Site of focus group was appropriate and comfortable;
- Participants found the activity very engaging and wanted to continue the discussion;
- Need for a resource directory with ability for consumer input/grading of services was articulated;
- Catering was well-received and appropriate for time of day.

Areas where there was a need for change or improvement included:

- Some questions were perceived as “leading questions”;
- More consumers should be included in the focus groups;
- More females should be included in the focus groups;
- Focus groups were too short; more time should be allotted to each group;
- Groups should be separated for those accessing care for the first time and those who have been in care for a considerable length of time;
- Questions should be separated for clients who receive all their services at one agency vs. those who receive services at multiple agencies;
- Questions and the facilitation of questions were confusing for some – were their experiences as individual consumers or their experiences in working with HIV/AIDS affected consumers being solicited – or both;
- Service categories alluded to in the discussion were not clearly presented;
- Core/ Non-core service categories were not defined at the outset of the activity;
- Lack of clarity regarding quality of service or need for service;
- Definition of special populations not clear;
- Consider focus groups for Spanish-speaking participants;

**NEW BUSINESS:**

A. Richardson will be going to the Lower East Side Harm Reduction Coalition on April 22 to discuss outreach to LEHRC’s clients re: Planning Council participation. J. Owens noted that there was a pledge for funds to underwrite participation to AIDS Watch at the end of April 2008 but that it has not materialized. M. Soares asked about the availability of a training on group communication/dynamics. In a review of the Planning Council By-Laws, V. Benadava reminded the group that there is no At-large Consumer Committee member who sits on the Executive Committee.

A motion was made:

**At the next Consumers Committee meeting, there will be a vote to elect a Consumers Committee member as the At-Large member.**

The motion was seconded and vote taken: the motion **passed unanimously.**

There being no further business, the meeting was adjourned at 4:10PM.