



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

Meeting of the Consumers Committee

May 14, 2008, 1:30PM – 4:00PM

Housing Works, 57 Willoughby Street, Brooklyn, NY

**Members Present:** Felicia Carroll (Co-Chair), Edilberto Viera, Jr. (Co-Chair), Victor Benadava, Orbit Clanton, Gregory Cruz, Manuel Ducret III, Billy Fields, Myron Gold, Juanita Owens, Glen Philip, Anthony Richardson, Marcelo Soares

**Members Absent:** Brent Backofen, Terri Faulkner, Hilda Mateo, Gonzalo Mercado, Alvin Perry, Aracelis Quinones, Escott Solomon, Robert Spellman

**Guests Present:** Timothy Benston (NYSAI), Ronald Brown, Yves Gebhardt, Tarasa Gill, Jolette Jones, Arthur Knight, Jesus Maldonado, Peter Messeri, PhD, Yvette Modica, Thomas Powell

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

### **Meeting Materials Distributed:**

- May 14, 2008 Consumers Committee Meeting Agenda
- May 2008 Planning Council Meeting Calendar
- April 16, 2008 Meeting Minutes
- “Employment & Economic Well-Being” CHAIN Report 2006
- “Consumers with HIV/AIDS: application of theory to explore beliefs impacting employment”, Hergenrather, K., Rhodes, S., Journal of Rehabilitation, Jan 1, 2008
- NYC HIV Planning Council At-Large Consumer Member position description & Election Ballot
- 2008 NYC HIV Planning Council New Membership Application

### **Welcome and Introductions:**

Felicia Carroll, Co-Chair, welcomed the group and announced that Alvin Perry, Co-Chair, has stepped aside due to health considerations. Edilberto Viera, Jr. has been chosen to assume the role of Co-Chair of the Committee for the remainder of the Planning Cycle and announced that it is his intention to insure that clients are receiving the best care possible. Participants introduced themselves and new participants were welcomed to the meeting. Myron Gold led the group with a moment of silence, noting the passing of Keith Shelton, husband of Patricia Shelton. Marcelo Soares reviewed the Rules of Respectful Engagement and Darryl Wong, NYCDOHMH, reviewed the agenda for the afternoon’s meeting. Felicia requested that members update their contact information, if necessary.

### **Review of April 16, 2008 Minutes:**

The minutes from the April 16, 2008 meeting were reviewed. Myron Gold and Glen Phillip noted that they were present at the March 2008 meeting. Marcelo Soares clarified that the request for the Ryan White Service Directory should be formatted with a satisfaction rating to assist consumers in selecting providers. A motion was made and seconded to accept the minutes; minutes were accepted.

### **May 2008 Planning Council Activities:**

Darryl Wong provided an update of Planning Council activities:

**The HIV Planning Council** will meet on May 15 where there will be a presentation of HIV Services on Riker’s Island led by the Division of Health Care Access & Improvement, which oversees health services

at the NYC jails. *The Integration of Care Committee* (May 28) will continue the discussion of the Care Coordination Model in development by the Bureau of HIV/AIDS Prevention & Control. *The Rules & Membership Committee* will also meet on May 28, where proposed By-Law changes and new membership recruitment activities will be discussed. It was noted that there will be a question as to applicants' prior participation in the Leadership Training Institute (LTI) initiative and applicants' willingness to participate in these trainings if selected for appointment. In addition, LTI will conduct a multi-day training on Communication and the Priority Setting & Resource Allocation (PSRA) process. *The Priority Setting/Resource Allocation Committee* met on May 1 where the PSRA tool undergoing revision was discussed. The Committee re-allocated the percentage weights for criteria factors, including Consumer Priority (25%) and Access to Care/Maintenance in Care (35%). Myron Gold emphasized the role that consumers can play, citing consumer involvement in the *Needs Assessment Committee* where the highest ranking emerging needs were: 1) MSM of Color, 2) Transgender HIV issues, 3) HIV in the over 50 population and 4) Women of Color. The highest ranking service gaps were 1) Housing and 2) Discharge planning services for individuals from NYC jails.

Marcelo Soares sought clarification on the 2008 Planning Council membership application process, asking why CAB participation or Consumer Advisory Board experience should not be included in the response to the question involving affiliation. Darryl Wong clarified that this question is included specifically to ascertain an individual's involvement as a paid employee, consultant or Board Member, and would be used in the context of conflict of interest during voting procedures.

### **PWA Advisory Group Update**

The Advisory Group met on Saturday, May 10 at GMHC and was well-attended. There was a CBO panel presentation on vocational training and return to work programs, featuring program directors and clients from Housing Works, Harlem United and GMHC. Three transgender individuals living with HIV/AIDS spoke about their personal experiences in accessing HIV/AIDS services and the challenges involving the lack of epidemiologic data/information and the paucity of funding directed towards this under-served population.

### **Breakout Sessions:**

- Victor Benadava, Chair of the *Primary Care and Support Services Sub-Committee* reported that the definition of Transportation services needs further fleshing out as part of the Care Coordination Model under development. Myron Gold reported that there were some service delivery challenges with the current contract.
- Myron Gold of the *Policy Sub-Committee* reported that 1) HASA 2) City Council stipends for PWA participation in the planning process, 3) Medicare and Medicaid changes, 4) HIV/AIDS issues that should be brought to the City Council, 5) Transgender HIV/AIDS issues, 6) HIV Care Network participation, 7) HATMA & Re-Authorization, 8) Newly-diagnosed individuals, 9) HIV in the over 50 year old population and 10) differently-abled individuals and HIV/AIDS services. It was also suggested that consumers should attend City Council hearings on HIV/AIDS issues, especially during the Public Comment period. Consumers were also reminded that above issues are not time-limited during the course of the planning year and that continuing discussions are part of ongoing policy development.
- Marcelo Soares of the *Recruitment & Membership Committee* asked that PWA Advisory Group flyers be supplied at the AG's table at AIDS Walk and shared his view that the breakout sessions allow little time to discuss relevant issues in-depth. He also announced that he is unable to continue in his role as Sub-Committee Chair of the committee due to time conflicts.

Dr. Peter Messeri of the CHAIN project presented on Employment and Economic Well-Being. The CHAIN project, which began in 1994, represents the voice of the consumer in the planning process. These studies are undertaken by the Mailman School of Public Health through a subcontract with the grantee; the NYC cohort of study participants has been interviewed three times since 2002. The focus of this survey was on current issues regarding employment and well-being: current trends and work experience, reasons against returning to work among the unemployed, common work related difficulties among the employed, individual household income and demographic factors and attributes of those currently-employed. Findings include:

- About 15% are currently at work and less than 5% are employed full-time, perhaps in the fear of losing entitlements;
- About 50% report they are not thinking of getting a job, about one third are thinking of getting a job;
- Those thinking about getting a job are motivated by financial needs and self-esteem;
- Lack of job skills and loss of benefits do not appear to be significant factors;
- There are significant concerns around medication side effects and adherence issues;
- Those living with HIV live economically precarious lives, reporting annual income between \$5,000-\$7,000 (part time) and \$15-25,000 for full time employment;
- 70% lacked funds to pay for rent, utilities, clothing, food and recreation; financial barriers are not preventing individuals from getting medications or services;
- Education, recent on-the job training, substance use problems contributed to whether one was employed or not; and
- About 30% of those who are feeling well are going back to work, with an increase to ~50% among those who are college-educated.

Myron Gold noted that many job training programs are geared towards harm reduction clients with the attendant risk that their health status is not or may not be stable, and that they may lack training qualifying them for employment. Members also reported stress from their budgeting activities related to their HASA entitlements; it was recommended that contact be made with VESID for SSI/SSD clients.

Jennifer Steele from Housing Works presented on the Second Life Job Training Program. Begun in 1994, Housing Works guaranteed that graduates would be eligible for fulltime employment at Housing Works. The 6-9 month program consists of two phases: Pre-vocational (soft skills, including GED preparation) and Vocational (On the job skills training) and is funded by the NYS DOH and the US Department of Labor. Clients with legal and financial issues work with the Case Management Team. Trainees are granted (8) days sick leave per quarter and leaves of absence per quarter.

### **Election of At Large Consumer Member**

Darryl Wong reminded those present that in order to run for this position, individuals must be members of the Consumers Committee; this position is for a short term period of two months until the close of the planning year. The motivation for filling this position is to insure as much consumer representation in the Executive Committee as possible.

Victor Benadava, Myron Gold, Gregory Cruz and Juanita Owens submitted their candidacies for the position of At Large Consumer Member, each making a three minute statement as to why they are seeking election. Ballots were distributed and collected; Edilberto Viera, Jr. announced that Gregory Cruz was elected as At Large Consumer Member.

**Leadership Training Institute (LTI):**

Gregory Cruz presented on the LTI initiative, which is modeled after the Planning Council structure: Effective Group Communication, Priority Setting & Resource Allocation, Understanding Data and Community Planning. There is also a new training for newly-diagnosed individuals in the areas of self-care and self-management, with pairing between new trainees and seasoned mentors. It was mentioned that they are seeking newly diagnosed individuals, those in care who dropped out and returned to care and those who dropped out of care and never returned to care. Although there are translation services available, because this program is in a pilot year, this is not a curriculum for individuals speaking only Spanish.

**Public Comment/New Business:**

- The LGBT Center will host a Health Fair on Thursday, May 22 for senior and older individuals.
- It was noted that there were few consumers present at the City Council meeting.
- Glen Phillip sought clarification on the notion that the proposed care coordination model is limited to a time period of six (6) months. It was clarified that while case management is not necessarily time limited, one measure of a program's success might be to gage the degree to which clients become self-sufficient.
- The HIV Care Network in Brooklyn is not yet operational.
- In response to a query regarding the interview process for Planning Council membership, it was clarified that there will be interviews conducted for candidates considered for appointment.

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