



Consumers Committee Meeting

June 17, 2009 1:30 - 4:45PM

Housing Works, 57 Willoughby Street, Brooklyn, NY

Members Present: Victor Benadava (Co-Chair), John A. Eddie (Co-Chair), Brent Backofen, Felicia Carroll, Gerald DeYounge, Antionettea Etienne, Billy Fields, Linder Ford, Yves Gebhardt (for E. Viera), Glen Phillip, Escott Solomon.

Members Absent: Anthony Case, Gregory Cruz, Myron Gold, Marcelo Soares

Guests Present: Eric Bartley, Ronald Brown, Patricia Clouden, Joseph D.V., Ron Joyner, Keith Kaiman, Mallory Marcus, Peter Messeri, Dr.PH, Thomas Powell, Jr., Jean- Louis "Sammi" Schmid, Joseph Sellman,

DOHMH: Mary Irvine, Dr.PH, Rafael Molina, Darryl Wong

Meeting Materials Distributed:

- June 17, 2009 Meeting Agenda
- Rules of Respectful Engagement
- May 20, 2009 Consumers Committee Meeting Minutes
- NY HIV Planning Council ByLaws, Article IX - Conflicts of Interest
- NYCAHN announcement, "City Budget Agreement Reached"
- Care Coordination RFP Task Force Minutes of May 4 & May 29
- Presentation Summaries and Recommendations from the Needs Assessment Committee: PLWHA Living in Single Room Occupancy Dwellings in NYC, Rev May 28, 2009
- NY HIV Planning Council Overview: Consumer Involvement in Quality Improvement
- Universal Voluntary Testing & Treatment for Prevention of HIV Transmission, Journal of the American Medical Association, Vol. 301, No. 22, June 10, 2009
- HRSA/HAB: Ryan White HIV/AIDS Program Part A Manual
- HRSA/HAB: HRSA Care ACTION, Positive Partners: Consumer Involvement in HIV Care, Sept 2002
- Primer: Understanding Community Advisory Boards, International AIDS Vaccine Initiative
- A Place at the Table: Having a Voice in HIV Planning & Decision Making, The Well Project, Feb 2006
- Joining a Community Advisory Board, December 20, 2003, The Body
- Community Advisory Boards, Intl Conf AIDS, July 2002, Abstract MoPeG4319
- Evolution of a participant-directed Women's Interagency HIV Study Community Advisory Board, Intl Conf AIDS, July 1996, Abstract Tu.D.2763
- Research & Development: Community Advisory Boards, Clinical Guidance: Essential Approaches for the Conduct of IAVI Clinical Research, International AIDS Vaccine Initiative

- The involvement of people living with HIV/AIDS in Community-Based organizations: Contributions and Constraints, AIDS Care, Vol. 13, Issue 4, August 2001, pp 421-432
- Report on a Workshop on Community Advisory Boards, Immuno AG CAB, April 1997
- Community Involvement: From Past to Present, Siskind, Division of AIDS, National Institute of Allergy and Infectious Diseases, September 2004
- Community Advisory Committee Guidelines: Victorian Public Health Service, Melbourne, Victoria, Australia, May 2006
- Obtaining Advisory Input from Consumers of HIV/AIDS Health Care Facilities, NYSDOH, AIDS Institute, 2004, Internal document
- PLWHA Advisory Group Resolution to the Planning Council, 6/13/09, Distrib. by A. Etienne
- CHAIN Project - Field test of new survey questions, June 2009, Distrib. by P. Messeri)
- July 2009 Planning Council Calendar

Victor Benadava and John Eddie, Co-Chairs, welcomed participants, followed by introductions. Billy Fields led the moment of silence in memory of PLWHA. Mr. Eddie reviewed the Rules of Respectful Engagement and Darryl Wong reviewed the agenda and meeting materials, noting that the meeting will be extended in order to accommodate a brief update by the Principal Investigators of the CHAIN study. The Planning Council's Conflict of Interest Bylaws were referenced and the minutes from the May 20, 2009 meeting were reviewed and approved with no changes noted.

HIV Planning Council Policy Updates:

Darryl Wong reported on the following activities:

- The CAEAR Coalition is meeting this week in Washington, DC., where discussion of the Ryan White program extension, pending HATMA's expiration/sunset on September 30, 2009, is occurring.
- The City budget was passed by the City Council, with full restoration of \$1.87 Million for HIV/AIDS supportive housing case management services and \$491,000 of the Momentum Project's nutrition programs. However, Scattered Site 2 did not receive any funding restoration, representing a \$4 million for HASA.
- Antionettea Etienne, Co-Chair of the *PLWHA Advisory Group*, announced her resignation from the Advisory Group and from the full Planning Council, due to health reasons. Rev. Gale Jones facilitated a stress-relieving session at the AG meeting. The Denver Principles, its precepts and its relevance today was the focus of the meeting, culminating in the AG adopting the resolution which was prepared and distributed by Charles King of Housing Works. Escott Solomon noted that PWA Board of Directors composition for large multi-disciplinary primary care centers, such as hospitals, could not be mandated due to the wide range of health care issues being addressed by such facilities. Billy Fields suggested that there be a presence of consumers to advise these facilities on service provision issues. John Eddie clarified that while HATMA provides guidance and direction for PWA involvement in planning activities, its purview does not include governance or administration of Ryan White funded-agencies. Darryl Wong referenced the accuracy of Mr. Eddie's remarks by citing HRSA/HAB Planning Council Part A guidelines from the Primer. Felicia Carroll urged the Committee to remain firm in their intent to see the resolution passed by the Planning Council.

ACTION: Joseph Sellman made the motion that the Consumers Committee support the AG's resolution, even to the point of coercing agencies to include consumers on their Boards. The motion was seconded and voted, passing with two abstentions.

- *Care Coordination RFP Special Task Force* met on Monday, May 4, 2009 and Friday, May 29, 2009; minutes of the Task Force were included in the meeting packet. It was noted that for the Care Coordination guidance, background materials were presented too quickly and materials were not provided far enough in advance for members to prepare effectively. In the future, the distribution of information and more advance notice of discussion and decision-making will be followed in order to accommodate substantive discussion.
- *The Memorandum Of Understanding*, which articulates both NYCDOHMH's and Planning Council roles & responsibilities in the planning process, was approved by the Executive Committee at its last meeting and will be then reviewed by the Legal Department of NYCDOHMH, before the final version is agreed upon.
- Mr. Wong reviewed the Committee's accomplishments during this planning year, which include presentations on the Medical Monitoring Project (MMP), the Quality Management initiative, HASA and housing options for PLWHAs and the Return to Work/Employment Initiative. In addition, the Committee provided feedback on the Consumer Focus Group Survey Protocol and the rollout of the series of 12 groups in March/April of 2009.

Community Advisory Boards (CABs):

- A survey questionnaire addressing the processes of consumer input for CABs, originally developed and utilized by the NYSDOH/AIDS Institute in 2004 was distributed for the Committee's use as a template/tool to be used to collect baseline data for the Committee's future work on the development and implementation of CAB guidelines. The report on the outcomes of this survey was included
- The meeting packet contains numerous references on the role of Community Advisory Boards and its implementation in a range of research and treatment settings; Committee members were strongly encouraged to review these references for the Committee's July meeting.
- Due to time constraints, comments and feedback on the survey questionnaire were deferred until the Committee next meets in July.

CHAIN (Community Health Advisory & Information Network) Update:

- The principal investigator of the CHAIN Study, Peter Messeri, DrPH, presented new pilot- test study questions to members of the Consumer Committee for comments and feedback, particularly from the perspectives of "user-friendliness", relevance, clarity, interpretation and difficulty in responding . It was stressed that the focus was not on the responses, but on improving the questions' relevance and clarity as they relate to identifying components of successful care coordination.
- Members offered the following comments:
 - Confusion on who is the "main HIV care provider" - agency or individual;
 - Clients may designate their main provider as one where they are most at ease;
 - Clarity between a Case Manager and a Social Worker;

- Treatment Adherence Counselors can also be peer educators, case managers, etc., depending on the title used;
- Transition issues - from one provider to another, or from adolescent to adult care;
- Alternative providers - holistic, pastoral, etc., should be listed as provider options;
- Providers may case conference (discussions, information exchange, electronic health records) but not necessarily meet in person;
- Consider reformulating statements into questions;
- Distinction between “wanting” and “needing” information, “where to go” vs. “who to see” for specific health concerns, “medical conditions vs. health and mental health, or environmental (housing) issues;
- Assuring that the language “resonates” and is meaningful to particular populations, i.e., adolescents.

Community Updates:

Sam from Cicatelli Associates announced the availability of trainings for Ryan White Part A.

Public Comment/New Business:

The Committee agreed to meet again on July 22, 2009 in order to continue the discussion. The Advisory Group will conduct its external meeting/picnic on Saturday, July 11.

Adjournment:

There being no further business, the meeting was adjourned at 4:45PM.