



Consumers Committee Meeting

December 17, 2008, 1:30-4:00PM

Housing Works, 57 Willoughby Street, Brooklyn, NY

Members Present: Victor Benadava (Co-Chair), John Anthony Eddie (Co-Chair), Brent Backofen, Felicia Carroll, Anthony Case, Gregory Cruz, Billy Fields, Linder Ford, Yves Gebhardt, Myron Gold, Glen Phillip, Marcelo Soares, Escott Solomon

Members Absent: Gerald DeYounge, Manuel Ducret III, Terri Faulkner, Gonzalo Mercado, Juanita Owens, Alvin Perry, Edilberto Viera, Jr.

Guests Present: Ronald Brown, Ronald Joyner, Joseph Sellman, Mark Misrok

DOHMH: Mary Irvine, DrPH, Rafael Molina, Jan C. Park, Darryl Wong

Public Health Solutions: Rick Goldfarb

Meeting Materials Distributed:

- December 17, 2008 Meeting Agenda;
- November 19, 2008 Meeting Minutes;
- Medical Monitoring Project (MMP) June 2008 Newsletter;
- NYSDOH Expert Panel Executive Summary: Defining the HIV Specialist, March 12, 2008;
- HIV Experience in the Future: Names, Numbers or Neither, Bruce D. Agins, MD, Medical Director, NYSDOH AIDS Institute, December 2007;
- 2008-9 At-Large Consumer Member Nomination Announcement & Voting Ballot;
- Consumer Input Strategies Discussion Questions, Mary Irvine, DrPH, NYCDOHMH;
- Ryan White Part A Grievance Procedures;
- 2009 NY HIV Planning Council: Consumers & Executive Committees & Full Planning Council Meeting Calendar;
- National Working Positive Information packet, including 2008 Vocational Training and Employment Survey, Penn State University.

Welcome and Introductions:

Victor Benadava and John Anthony Eddie, Co-Chairs welcomed participants with staff, Committee members and guest introductions. Myron Gold led the moment of silence, John Anthony Eddie reviewed the Rules of Respectful Engagement and Darryl Wong reviewed the agenda and meeting materials for the afternoon's meeting.

Review of the October 22, 2008 Minutes:

The minutes from the November 19, 2008 were reviewed. Motion made to accept minutes, seconded and voted. Minutes were accepted.

Consumer Committee Minutes December 17, 2008

HIV Planning Council Update:

Mr. Park announced that at the December 18 HIV Planning Council meeting, there will be presentations on 1) Medicaid reforms and APGs, 2) the 2009-12 Comprehensive Strategic Plan and 3) the Care Treatment & Housing Program of the Bureau of HIV/AIDS Prevention & Control. Also, the election of the Planning Council's Finance Officer will take place. The Planning Council Orientation will be held on Monday, January 5, 2009 at St. John's University at 101 Murray St., New York, NY from 12-5 PM. In addition to Planning Council members and their alternates, all Consumer Committee members are invited to attend.

Felicia Carroll updated the Committee on the December 13th Advisory Group meeting at Iris House, where Dr. Peter Messeri presented on HIV & Co-Morbid Conditions. Antionettea Etienne was re-elected as the Planning Council Co-Chair of the AG. Marcelo Soares inquired if deaths from non-HIV related causes were increasing because of longevity or because of other factors.

Mr. Wong reviewed the MMP June 2008 newsletter published by CDC, one of the funders of the project. Mr. Eddie reviewed the announcement of the 2008-9 At-Large Consumer Member, who will hold a seat on the Executive Committee. After reviewing the time commitments for this position, Gregory Cruz, Myron Gold and Glen Phillip made individual statements on their qualifications and motivations for seeking election. Gregory Cruz was elected as the At-Large Consumer Member for 2008-09.

National Working Positive Coalition:

Mark Misrok, Board Chair of the National Working Positive Coalition (www.workingpositive.net) presented on the Coalition's main goal of connecting individuals who are interested in the economic advancement of people with HIV so that resources and knowledge can be shared and have a greater impact on achieving the goal of improving educational, vocational and employment opportunities for people living with HIV/AIDS. Members were invited to use the sites resources and to join workgroups on 1) Research, 2) Employment Programs and Service Approaches or 3) Policy and Advocacy. The Coalition promotes research to better understand the financial needs and complex challenges facing individuals with HIV, promote the development and evaluation of effective practices in employment services and advocate for work options and access to financial resources that are consistent with the personal and health needs of people living with HIV/AIDS.

Mr. Misrok distributed an information packet, which also included a research study being conducted at Penn State University, in both English & Spanish, on Vocational Training and Employment for people living with HIV/AIDS and asked for members' assistance in disseminating this survey throughout their service networks and communities. Members' questions/comments/concerns included:

- there is little data available on how many people have been employed, left for health reasons, went off Medicaid, or have transitioned between employment and unemployment;
- relative stigma & discrimination issues faced by people living with HIV/AIDS vs. cancer or other life-threatening diseases;
- psychological issues involved when transitioning from long periods of unemployment, when there were few life-sustaining treatments, to the current medical environment where both ability and desire to return to employment due to better health outcomes is increasingly more common;
- societal, political and structural attitudes and barriers toward disabilities, aging, etc;
- social service agencies constraints in providing services to those who can be more employed, but choose not to be so that services are not lost;

Consumer Committee Minutes December 17, 2008

- keeping the momentum of interest at a high level in order to continue developing national and outcome-oriented discussions on employment issues; and
- the lack of employment services, discussions or resources at CBOs where clients are seeking medical and social services.

Consumer Input Strategies:

Mary Irvine, DrPH of the PPI continued the discussion on consumer input for the 2009 Priority Setting Process. At the last meeting, the re-commitment to repeating in 2009, consumer focus groups with a broader spectrum of consumers (including gender, age, primary language) and in more areas of the city was affirmed. Consumers are currently being asked to provide input on which content areas need further exploration and which groups need to be queried. Prior to this meeting, Dr. Irvine re-articulated the following questions, which were distributed to all Committee members to allow them time to reflect on responses:

- What are the major/most important topics, issues, or concerns on which we should seek consumer input?
- What types of information do we want to get through surveys (with more than 50 people answering the same questions, in a structured, mostly closed-ended question format)?
- What types of information do we want to get using an in-depth, open-ended format, like the format for focus groups?
- Is there a specific priority population or group of consumers that we want to be sure we hear from? For example, should we be focusing on those who have been disconnected from HIV care? Should we be focusing on the current members of Ryan White service provider Consumer Advisory Boards? Should we be focusing on clients in one Ryan White service category? Should we be focusing on older or younger consumers?

Issues raised by the Committee, and possible data sources, include:

- Question (1) :
 - Funding cuts and effects on services
 - Housing issues
 - Substance abuse/treatment adherence relationship
 - Self-advocacy/self-reliance/vision of future
 - Stigma, discrimination
 - HIV medication side effects
 - Women & children
 - Emerging needs
 - Informed consent/patient rights
 - Back to work motivation
 - Awareness campaigns
 - Managed care
 - Transportation services
- Data Sources
CHAIN (needs), FGs,
CHAIN questionnaire
- CHAIN study

Dr. Irvine suggested that the Housing outline from the CHAIN survey & MMP be distributed to inform further comments and that the comments from Consumers be summarized & developed, describing the different approaches of structured, closed-end surveys from more open ended, in-depth probing surveys (better for expressing opinions or beliefs). Those who responded to the preliminary questions stressed that the survey should reach broad and diverse populations, including African Americans, younger and older individuals, commercial sex workers, IDU history, those who are not receiving services and consumer advisory boards of funded agencies. Mr. Wong suggested that the input question discussion forms be completed and sent to NYCDOHMH for review and incorporation.

DRAFT Consumer Committee Minutes December 17, 2008

Consumer Committee Minutes December 17, 2008

Dr. Irvine informed the Committee that it is NYCDOHMH intent to repeat the focus group format in 2009; with respect to the role of Community Advisory Boards (CABs) in gathering data, Part A service planning is more difficult because there is no standardization of operational guidelines or procedures. Rather, the consumers who are captured by the CAB surveys represent activated, motivated and engaged consumers, which may or may not be representative of the entire Part A client spectrum. Input on questions for the CHAIN survey should be submitted to NYCDOHMH as soon as possible. There are three months remaining in the priority setting process and executing both focus groups and CAB surveys may be a strain on staffing resources. If there were a CAB survey conducted, every person on the CAB would need to be surveyed, which represents logistical challenges. It is also not clear what can be done with the results from the CAB survey.

Ryan White Part A Grievances:

Rick Goldfarb of HIV Care Services of Public Health Solutions presented on the client grievance process established by Public Health Solutions (HIV Care Services) and mandated by HRSA and the contracting process, distributing the grievance policy and client grievance forms. Any client or staff member can file a grievance. After pursuing internal options, a grievance can be filed with HIV Care Services. It was underscored that grievances are taken very seriously. There is a time limit of three days for a response to be initiated and a twenty day window for an issue to be resolved. For more information, please refer to the grievance policy and handouts. Mr. Gold informed the Committee that at some agencies, the grievance process is stifled, there is little knowledge about the process and clients are afraid of recrimination, even though one may file anonymously. Mr. Sellman noted that there is a perception that HIV Care Services favors the service agencies in their final determinations.

Mr. Wong spoke about Planning Council and grantee, or DOHMH-level grievances, with the principal difference being a violation of the *planning process*, including priority setting/resource allocation, nominations and deviations from Planning Council bylaws, as opposed to the *contracting process*, which is directed to NYCDOHMH, as grantee. In the case of a Planning Council grievance, the grievance is brought to the attention of the Planning Council office; grievances against the NYDOHMH can be directed to the Commissioner of Health.

Public Comment/New Business:

The Declaration of Human Rights celebrated its 60th anniversary on December 10; the Planning Council was asked to endorse this document. There was a consensus for this document to be adopted by the Policy Committee and the NY HIV Planning Council. Mr. Joyner sought clarification as to whether peer educators need to be certified. Mr. Cruz clarified that they will need certification if they are HIV specialists, legislative discussions are ongoing.

There being no further business, the meeting was adjourned at 5:00.