



Consumers Committee Meeting

November 19, 2008, 1:30-4:00PM

Housing Works, 57 Willoughby Street, Brooklyn, NY

Members Present: Victor Benadava, Manuel Ducret III, Billy Fields, Linder Ford, Yves Gebhardt, Myron Gold, Glen Phillip, Escott Solomon

Members Absent: Brent Backofen, Felicia Carroll, Anthony Case, Gregory Cruz, Gerald DeYounge, Terri Faulkner, Gonzalo Mercado, Juanita Owens, Alvin Perry, Marcelo Soares, Edilberto Viera, Jr.

Guests Present: Ronald Brown

DOHMH: L. Perry Brothers, Mary Irvine, DrPH, Rafael Molina, Alan Neaigus, PhD, Jan Carl Park, Anthony Santella, DrPh, Darryl Wong

Public Health Solutions: Rick Goldfarb

Meeting Materials Distributed:

- November 19, 2008 Meeting Agenda
- October 22, 2008 Meeting Minutes
- Draft Comprehensive Strategic Plan for HIV/AIDS Services 2009-12
- CHAIN project description
- Medical Monitoring Project (MMP) presentation
- Consumer Involvement Strategies & Practices, pp 20-27, NYSDOHAI,
- A guide to Consumer Involvement of Improving the Quality of Ambulatory HIV Programs
- Consumer Focus Group Results, Irvine, Santella & Fryer, June 2008
- NYC Ryan White CARE Act Title I Consumer Advisory Group Survey Report, April 2006
- Guidelines for Ryan White Part A Providers on Advisory Boards
- November 2008 NY HIV Planning Council Calendar

Welcome and Introductions:

Victor Benadava, the newly-appointed Co-Chair of the Consumers Committee welcomed participants with staff, Committee members and guests introductions. Escott Solomon led the group with a moment of silence. Myron Gold 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 October 22, 2008 were reviewed. The motion was made, seconded and the minutes were accepted (by consensus).

Planning Council Update: Jan Park & Darryl Wong

Membership of the 2008-9 Planning Council: The Mayor's Committee on Appointments has confirmed the appointments of (14) individuals for the 2008-9 Council and (4) continuing members who are serving their

second term. The Planning Council will meet on Thursday, November 20 at the LGBT Center at 208 W.13th St. New York. As noted, Victor Benadava has been appointed as Co-Chair of the Consumers Committee for the current planning cycle; the 2nd Co-Chair will be appointed shortly, pending notification from the individuals who have been offered the Co-Chairperson slot. Nominations will be open for one month for the At-Large Consumer member, who is not a Planning Council member, but has a seat and vote on the Executive Committee, in addition to the two (2) Co-Chairs. The election of the At-large Consumer member will take place at the December 17, 2008 Consumer Committee meeting.

PWA Advisory Group: More than fifty (50) individuals participated in the Saturday, November 15 meeting at which the AG's by-laws, advocacy on housing issues, proposed Medicaid changes and planning for a consumer forum projected for April 2009 were discussed. The Planning Council Co-Chair of the AG has not yet been appointed due to the delay in the Planning Council new member appointment process.

Discussion of the 2009-12 Comprehensive Strategic Plan: Anthony Santella, DrPh & Mary Irvine, DrPH. A. Santella provided an update on activities of the Policy, Program & Implementation (PPI)Unit:

- The Needs Assessment, Integration of Care, Tri-County Steering Committee and Executive Committee have reviewed and provided feedback on the Strategic Plan;
- The Internal DOHMH workgroup has incorporated changes into the draft being reviewed, beginning on page 39;
- Responding to the need for more description on core services, an additional goal (6) was added, to insure that psychosocial and support services, including harm reduction, meet the needs of PWAs in the EMA. The current goal focuses on unmet need and under-utilization, i.e., a service may be available but not accessed, with a view towards the degree to which the system is achieving its purpose, when the need is recognized;
- The New York Academy of Medicine will be approached to act as an external reviewer;
- 95% was selected as the threshold for medication adherence; and
- The Monitoring & Evaluation Chapter, beginning on p. 51, is still incomplete, pending the receipt of data. A review of data sources was provided, beginning with:
 - **HIV/AIDS Surveillance Data:** Clinical indicators such as CD4s, viral load, test dates (as indicators of engagement in care) and mortality rates are available through the HARS. While the data are representative of the EMA's epidemic (including Tri-County), but there is a 9 month lag time in reporting, resulting in a 2007 epidemiologic baseline for planning. It does not include data on undiagnosed (non-tested and non-positive) HIV cases. Because of its breadth of coverage, it is not useful for focusing on Ryan White services and utilization.

Consumer Input Strategies:

Nina Rothschild, DrPH presented a summary of the **CHAIN Study**. This project, funded by the Planning Council, is an ongoing prospective cohort study begun in 1994 of PWA in NYC and Tri-County region, is comprised of data based on measures in the CHAIN, two hour questionnaire and includes data on behaviors, perceived health status, satisfaction with services, relationship with primary care providers and perceived need for services. Due to the non-inclusion of patients receiving care at private medical practices, it under-represents white males and females, while its study demographics are more in line with Ryan White client population.

The survey is conducted once per year, with cohorts refreshed every few years using randomized selection at selected agencies in order to increase representativeness. Currently, 2006-7 baseline data is available, with more interviews to be conducted during Summer 2009. Meeting participants commented on the completeness of the survey, the use of questions from a wide range of issues, from which data is analyzed to inform policy issues/changes, e.g., housing, rental increases and domestic violence, the survey's use as a measure of consumer self-efficacy, the commendable efforts expended to locate prior survey participants who have re-located or been out of communication, and representation of the Planning Council, through the Needs Assessment Committee and consumer community, on the CHAIN Technical Review Team (TRT). A list of completed studies is available from the Planning Council website at www.nyhiv/data.org.

Dr. Alan Neaigus, Director of Research and L. Perry Brothers presented on the **Medical Monitoring Project**, with an accompanying handout. The MMP is a national (26 project areas), CDC-funded study conducted by the NYCDOHMH HIV Epidemiology and Field Services Program, which aims to yield a better understanding of the health-related needs of NYC PWAs and examines medical care access and utilization, preventive and social services interaction/utilization, risk behaviors, clinical outcomes and data on emergency hospitalization, through 1 hour interviews and random chart reviews for ~ 400 patients from 25 randomly-selected public and private medical care providers throughout NYC, except Staten Island. 2007 data collection is complete and will begin again in December 2008. In the past, the Consumers Committee has acted as the local Community Advisory Board (CAB) for the project, reviewing outreach brochures and providing input on the local MMP questionnaire; the Committee will have another opportunity for input in the questionnaire in 2009. National comparisons are forthcoming pending further data analysis.

Rick Goldfarb of HIV Care Services of Public Health Solutions spoke on the role of **Community Advisory Boards (CABS)**. HRSA guidelines address the role of CABS established by Part A funds and specific contractual language defines their structure and monitoring. The intent is to insure that programs are accountable to their individuals and communities they serve; CABS may be representative of either the entire agency, the HIV programs, or only the Ryan White-funded programs and have clearly defined visions, goals and objectives, documented by formal meeting minutes. The CAB should be composed of all stakeholders – clients, families, providers and have operating procedures and protocols, including membership, participation and grievances, in place. Committee members raised concerns that 1) at some agencies, there is involvement by Agency management in evaluation and client satisfaction surveys, 2) the structures of the Advisory Board or Advisory Group allow for different operating procedures and 3) there are different monitoring standards in place at different agencies. Grievances against an agency's CAB should be directed to the Agency management before being referred to HIV Care Services.

Mary Irvine, DrPH of the PPI discussed consumer input for the 2009 Priority Setting Process. This past Spring, a **Return to Care survey** was conducted at 5 sites with 51 consumers who had fallen out of HIV care for nine (9) months and who were re-engaged into care at Maintenance in Care contract providers, focusing on reasons for dropping out of care, factors affecting re-engagement and which services were most critical or life sustaining. A draft report will be issued shortly. **Consumer Focus Groups** were conducted among 40 individuals which allowed consumers to express individual perceptions of importance and priority of service categories, which needs were best met, gaps in service delivery, geography and among special populations and overall satisfaction. The report was issued last year and is also available on the Planning Council website. There is a 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.

Consumers were queried as to what content areas need further exploration and which groups need to be queried. Those in care represent very different populations from those who are not part of the service system. The suggestion was made to allow Committee members to think about their responses in advance of the December meeting. Some questions that may help to focus efforts at gathering consumer input in 2009 include:

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- 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?

Dr. Irvine reminded the Committee that in order avoid duplication, we should begin planning for new consumer data collection activities from those of the ongoing CHAIN and MMP projects; new recommendations can be compared to existing data sources so that we can identify gaps where new data and qualitative information is needed for either priority setting or for process/infrastructure analysis, i.e., challenges with CABs, etc.

Public Comment/New Business:

B. Fields voiced his concerns about the lack of sufficient heat in HASA-sponsored apartments and the lack of redress. M. Gold echoed complaints about substandard living conditions with rodent infestation. He was advised that there is a HASA representative on the Planning Council, Sallie Adams, and that his complaint should be aired at that time.

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