



HIV Health and Human Services Planning Council of New York

Meeting of the Consumers Committee
February 13, 2008
GMHC, 119 West 24th St, Room 410, NY, NY
1:30-3:30 pm

Members Present: Victor Benadava, Felicia Carroll, Gregory Cruz, Manuel Ducret, Billy Fields, Glen Phillip, Mervin Otero

Members Absent: Brent Backofen, Orbit Clanton, Antionettea Etienne, Terri Faulkner, Linder Ford, Myron Gold, Hilda Mateo, Gonzalo Mercado, Juanita Owens, Alvin Perry, Aracelis Quinones, Anthony Richardson, Marcelo Soares, Escott Solomon, Robert Spellman, Edilberto Viera, Jr.

Guests Present: Timothy Benston (NYSDOH, AIDS Institute), Ronald Brown, Luis Felipe, Robert Jones, Joseph D. U., Carmen Maldonado, Miguel Mora, Israel Otero, Luis Quisos, Ronald Brown, Yves Gebhardt,

DOHMH: Daniel Weglein, MD, MPH, Mary Irvine, DrPH, Rafael Molina, Nina Rothschild, Planning Council Staff Liaisons, Darryl Wong, Consumers Committee Staff Liaison.

Meeting Materials Distributed:

- February 13, 2008 Consumers Committee Meeting Agenda
- February 2008 Planning Council Meeting Calendar
- January 16, 2008 Meeting Minutes
- February 11, 2008 Letter to Consumers from Jan Park, Fabienne Laraque & Daniel Weglein of the Office of HIV Care, Treatment & Housing, Bureau of HIV Prevention & Control, NYCDOHMH
- January 16, 2008 Consumer Committee Comments to 2006 CAB Survey
- Consumer Focus Group Guide – Draft 2/12/08 (by M. Irvine)
- Return to Care Survey – Draft 2 – February 2008 (by M. Irvine)
- February 11, 2008 New York Times article, “Scientists Find New Receptor for HIV”

Welcome and Introductions:

Felicia Carroll, Co-Chair, welcomed the group. Alvin Perry is out of town and unable to attend. Participants introduced themselves and Manuel Ducret led the group with a moment of silence. Victor Benadava reviewed the Rules of Respectful Engagement and Darryl Wong, NYCDOHMH, reviewed the agenda for the afternoon’s meeting. Before beginning the discussion of Consumer Input Recommendations, Mr. Wong read the letter which was distributed to Consumer Committee members from Jan Park and Drs. Laraque and Weglein of the Bureau of HIV Treatment & Control, NYCDOHMH regarding the proposed Consumer input process for Spring 2008.

February 2008 Planning Council Activities:

Announcements of the February 2008 Executive Committee and full Planning Council meeting were made and meeting participants were urged to attend.

Review of January 16, 2008 Minutes:

The minutes from the January 16, 2008 meeting were reviewed. Changes were made to attendance status of two members. Motion was made to accept minutes; vote taken, minutes accepted

Advisory Group Executive Committee & Planning Council Update:

The Executive Committee of the HIV Planning Council PWA Advisory Group met on Friday evening, February 8 where the issues of leadership and AG membership participation and the roles of the (3) Sub-Committees (Recruitment & Membership, Primary Care & Support Services and Policy), in the context of the larger decision-making process, were discussed. While in most cases there has been meaningful leadership participation, general membership participation at these Sub-Committee meetings has been lacking.

The following Sub Committee updates were given by the respective Co-Chairs:

Primary Care & Support Services: Victor Benadava reported that this Sub-Committee has been reviewing the former CAB survey and its usefulness in measuring consumer need. He also mentioned the possibility of holding this Sub-Committee meeting, and others, during the Advisory Group meetings, which are held on the second Saturday of each month.

Policy: Gregory Cruz reviewed current policy issues being discussed, including the NYS-funded HIV CARE Networks, newly diagnosed individuals who lack access to care, criteria used to identify emerging/special populations (ethnicity, physical challenges and abilities), the landscape in NYS regarding possible mandatory managed care & its relationship with Special Needs Plans (SNPs) and the clients they serve and Ryan White HATMA and the to-be-developed provisions for re-authorization, including prevention initiatives.

Discussion of Consumer Input Recommendations:

Mr. Wong introduced Mary Irvine, DrPH and Dr. Daniel Weglein, of NYCDOHMH, who will be introducing and discussing the proposed approaches for gathering consumer input in 2008.

Dr. Irvine has worked in HIV community prevention planning and research & evaluation in HIV treatment adherence programs. Manuel Ducret mentioned that there will be increased testing at NYC Housing Projects in the Bronx and that there may be more HIV+ clients to be served.

Dr. Weglein began the discussion by reviewing the broad goals of soliciting consumer input, through samples such as focus groups and population-specific surveys. Some members who expressed concern over the elimination of the CAB survey.

Dr. Irvine reiterated the need to capture information and feedback which can be used to assist in the prioritization of consumer needs and to also get a sense of what is working and what is not, which services are most needed and utilized and what barriers to these services exist.

Two approaches were discussed: 1) having open-ended discussions, in 2-3 focus groups of 5-15 participants, with Consumer Committee and Advisory Group Sub-Committee members speaking about populations with which they either work or are familiar and 2) surveying individual clients who, having been formerly lost to care, i.e., more than 9 months without services, are now re-connected to HIV care through a small number of Ryan White-funded Maintenance in Care contracts, initiated in 2007.

V. Benadava voiced the concern that patients not be accessed exclusively through these programs, but through other Ryan White- funded services as well.

M. Ducret shared that many, if not all clients, who are receiving housing, social and other services are usually obligated to have regular medical care as part of the provision of their other care.

G. Cruz sought clarification of the relative merits and limitations of the purposes of both approaches.

G. Philip asked for clarification for reaching those who are not presently in care, have not ever been in care and may never be in care. Dr. Weglein responded that the numbers of this last group may be overstated, in view of the fact that at some point, some medical care may have been accessed.

Meeting participants then took the opportunity to review the drafts individually or in small groups.

Dr. Irvine reiterated that neither instrument is designed to be a CAB survey. The Focus Groups are facilitated discussions and are not designed to be agency-based or affiliated with specific programs, but rather to capture a broad- based audience.

Y. Gebhardt suggested that HIV CARE networks be approached, as gateways to larger, more geographically and ethnically representative bodies.

V. Benadava suggested that Consumer Committee members could run the focus groups; Dr. Irvine reminded the group that experienced facilitators need to be identified in order to assure the integrity of the information collected.

R. Jones voiced concerns about time constraints and reminded members that we must proceed with what is being proposed in order to have some data with which we can move forward for planning purposes.

M. Otero clarified that the goal, as previously stated, is not to sample the entire population of NYC residents living with HIV, but rather to capture a sample of this population.

F. Carroll added that Advisory Group participants would provide a good sampling of individuals; G. Philip reminded the Committee that at the Brooklyn HIV CARE Network meetings, the lead agency has never been represented at these meetings.

D. Wong reviewed the Priority Setting/Resource Allocation prioritization process and the need to collect and then utilize data which is relevant to and reflective of current consumer needs. Dr. Irvine added that Focus Groups need to be completed in March in order for data to be analyzed in April and May.

G. Cruz suggested that questions probe about gaps in services that may not be received by the client, that survey questions be simplified in order to be more user-friendly and that supportive services, e.g., holistic services, be included as a separate type of service.

V. Benadava expressed concern about the impartiality of the focus group facilitator chosen by NYCDOHMH to record, as usefully and meaningfully as possible, comments elicited by this process.

M. Ducret expressed concerns around eliciting information around gaps for clients who are receiving services from multiple agencies vs. clients who are receiving services from a single multi-service agency, in addition to individuals who are not receiving any services from any agency.

M. Otero brought up the issue of offering focus group participant incentives to help assure greater participation.

D. Wong suggested that a follow-up feedback session be scheduled so that drafts may be reviewed in detail, comments recorded and re-integrated into the final statement. He also reminded Committee members that NYCDOHMH intends to honor the spirit and intention of this information-gathering process in order to maximize its usefulness and thanked Drs. Weglein and Irvine for presenting these drafts to the Committee. In closing, he suggested that available meeting timeframes for those interested in contributing feedback be communicated to him so that a time convenient for most could be chosen for the group to re-convene during the week of March 25. Any specific comments or questions regarding the draft instruments themselves can be emailed directly to him at dwong@health.nyc.gov

There being no further business, the meeting was adjourned.

