



HIV Health and Human Services Planning Council of New York

Meeting of the Consumers Committee

March 19, 2008

Housing Works, 57 Willoughby Street, Brooklyn, NY

12 Noon – 5:00PM

Members Present: Brent Backofen, Victor Benadava, Felicia Carroll, Gregory Cruz, Manuel Ducret, Antionettea Etienne, Billy Fields, Linder Ford, Ron Joyner, Mervin Otero, Juanita Owens, Anthony Richardson, Marcelo Soares, Edilberto Viera, Jr.

Members Absent: Orbit Clanton, Terri Faulkner, Myron Gold, Hilda Mateo, Gonzalo Mercado, Alvin Perry, Glen Phillip, Aracelis Quinones, Escott Solomon, Robert Spellman

Guests Present: Timothy Benston (NYSDOH, AIDS Institute), Yves Gebhardt, Matt Lesieur, Yvette Modica, Tamara Oyola-Santiago, Joseph Sellman

DOHMH: Anthony Santella, DrPH, Jan Carl Park, Darryl Wong, Staff Liaison.

Meeting Materials Distributed:

- March 19, 2008 Consumers Committee Meeting Agenda
- March 2008 Planning Council Meeting Calendar
- February 13, 2008 Meeting Minutes
- Bureau of HIV/AIDS Prevention & Control Organizational Chart
- Consumer Focus Group Guide – Draft 2/12/08 (by M. Irvine)
- Return to Care Survey – Draft 2 – February 2008 (by M. Irvine)

Welcome and Introductions:

Felicia Carroll, Co-Chair, welcomed the group. Alvin Perry is ill and unable to attend. Participants introduced themselves, Mervin Otero led the group with a moment of silence and Committee members were updated with news of Myron Gold. Gregory Cruz reviewed the Rules of Respectful Engagement and Darryl Wong, NYCDOHMH, reviewed the agenda for the afternoon's meeting. A public comment/new business period will be added to meeting's agenda.

Review of February 13, 2008 Minutes:

The minutes from the February 13, 2008 meeting were reviewed. Motion was made to accept minutes; vote taken, minutes accepted

March 2008 Planning Council Activities:

Jan Park provided an update of Planning Council Committee activities:

The Policy Committee has been involved in the development of two letters. The first addresses a change in policy which will impose a 24 month maximum lifetime cap on the utilization of short-term and emergency housing assistance and the second addresses increased funding for national HIV/AIDS programs. *The PWA Advisory Group Executive Committee* featured several women who shared their experiences living with HIV/AIDS. Future topics will include publicly-funded transportation services and transgender health issues.

The Priority Setting/Resource Allocation Committee approved the preliminary 2008 spending plan/budget which was then moved to the *Executive Committee* for consideration and approval. *The Tri-County Steering Committee* approved their 2008 Spending plan and budget. *The Executive Committee* reviewed the PSRA-approved budget and will be presented to the full *Planning Council* on March 20. It will be proposed that funds be restored into mental health services and added to treatment adherence, harm reduction/recovery readiness/relapse prevention services, early intervention services for the purchase of HIV test kits and case management services. Maintenance in care programs, which seek to return lost clients to care, will also be enhanced with additional funds, subject to Planning Council approval. *The Integration of Care Committee* considered a new model of integrated case management. The full *Planning Council*, to be held March 20, will vote on and approve the 2008 spending plan & budget. *The Finance Committee* will, by conference call, review the expenditures of the grant on a quarterly basis and other spending issues. *The Rules & Membership Committee* will be meeting to review the By-Laws of the Planning Council, which includes recruitment, nomination and appointment of new individuals.

Participants were encouraged to attend and participate in as many meetings as they wish.

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Advisory Group Executive Committee & Planning Council Update:

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.

