



CONSUMERS COMMITTEE

Wednesday, May 18, 2011, 1- 3PM

Cicatelli Assocs., 505 Eighth Avenue, 20th Fl. Lavender Rm, NY, NY

Planning Council Members Present: Victor Benadava (Co-Chair), John A. Eddie (Co-Chair), Gerald DeYounge, Alexander Hardman, Keith Kaiman, Munying Hunt, Deborah Marcano

Planning Council Members Absent: Brent Backofen, Felicia Carroll, Steve Hemraj, Hilda Mateo, Pastor Jerome Payne

Community Members Present: Derrick Chandler, Gregory Cruz, Colombia Fierro, Yves Gebhardt, Delores Henley, Ron Joyner, Joey Lopez, Myron Gold, Glen Phillip, Jacqueline Williams

Staff: DOHMH: Yoran Grant, Ph.D., Graham Harriman, Beau Mitts, Rafael Molina, Jan Carl Park, Darryl Wong. PHS: Gucci Kaloo

MEETING MATERIALS DISTRIBUTED:

- Meeting Agenda/Planning Council Ground Rules of Respectful Engagement/Rules for Public Comment;
- March 14, 2011 & April 20, 2011 Draft Meeting Minutes;
- Early HIV Therapy Sharply Curbs Transmission, NY Times, May 12, 2011;
- ADAP Watch List, NASTAD, May 2011;
- HIV/AIDS Policy Notice, 11-01, Federal Register, Vol 76, No. 92, 5/12/2011
- Letters to DHHS Secretary Mike Leavitt (2008) & HRSA/HAB Administrator Wakefield (2010) from the NY Planning Council;
- Medci
- Positive Voice, National Association of People With AIDS (NAPWA), April 23, 2011;
- MMP Community Fact Sheet – March 2011;
- Cancer Burden in the HIV-Infected Population in the U.S., Journal of the National Cancer Institute, April 11, 2011;
- NY HIV Planning Council 2011-12 Council Membership Application;
- May 2011 Planning Council Calendar & Month at a Glance;

INTRODUCTIONS:

John Anthony-Eddie opened the meeting, followed by Committee member introductions. Joey Lopez led the moment of silence and the meeting participants reviewed the Rules of Respectful Engagement. The minutes of the April 2011 meeting were reviewed and approved when quorum was reached. Darryl Wong reviewed the meeting agenda and meeting materials.

PUBLIC COMMENT:

Myron Gold voiced his disappointment that only two members of the PLWHA Advisory Group, including himself, spoke out against the Planning Council decision to suspend the Advisory Group. Ron Joyner and Gerald DeYounge stated that they felt that consumers should be more pro-active and inclusive in voicing their concerns at the Committee.

FEDERAL HIV/AIDS POLICY UPDATE:

Jan Park, Governmental Co-Chair provided an update on the status of the EMA Part A award, noting that while budget discussions continue, continuing resolutions are keeping the government operational. The FY 11 budget has been passed, funding activities through this fiscal year. The shortfall in funds will affect the Depts. of Health & Human Services and Education, which will result in a 0.2% reduction, at a minimum, for the NY EMA. In the past NY has received its award in April; currently, the anticipated date for release of award information is May/June. We anticipate that programs will suffer deeper cuts in FY12, with ADAP funding a major concern while the waiting list grows to ~ 8,000 PLWHAs. Mr. Park shared the CAEAR (Cities Advocating for Emergency AIDS Relief) Coalition's talking points for their most recent advocacy and lobbying visit to Capitol Hill, which continue to highlight the disproportionate impact and high demand for services for PLWHAs in NYC. Notably, the Ryan White program has been acknowledged, at a bipartisan level, as successful. This year, the issue of job creation for PLWHAs and its contribution to the US economy has been a discussion point, as well as the economic impact of states' budget on local HIV/AIDS prevention and treatment/care programs.

The Ryan White program expires in 2013 and will need an act of re-authorization to continue the legislation or to re-configure, given the projected implementation of Health Care Reform in 2014 and the 2012 national elections (and resultant majorities in House & Senate). Currently, wraparound services which comprise the continuum of care in NYC include housing and legal assistance, food & nutrition services, mental health services and enhanced medical case management, as it is delivered in NYC, without regard to citizenship status.

New York State has passed its final budget, with reductions affecting many sectors, but sparing the NYSDOH AIDS Institute and ADAP program. The Medicaid Redesign Team is continuing its work in shaping the program in anticipation of 2014.

Locally, HASA has generated much concern, particularly around Local Law 49 and maintaining the level of service currently provided by HASA case managers for 45,000 consumers. Currently, a lawsuit is underway contesting these budget cuts. Mr. Gold informed the group that HASA no longer provides Metrocards to clients who come for their re-authorizations. Medicaid will no longer be paying for nutritional supplements or stockings for diabetics and has imposed a home care cap of \$26,000/year and a cap of 20 visits/year for physical therapy.

The RMC has recommended a slate of sweeping reforms, generated by the discussion of PC and committee members and the recent HRSA technical assistance site visit. Of particular interest was the role of the PLWHA Advisory Group and why NYC has two consumer groups offering input into the planning process, which are both fiscally supported by HRSA funds. Other changes include mandatory training, lengthening of members' terms to three year terms, the elimination of Planning Council alternates and limiting the voting power of the grantee (DOHMH) in process deliberations. This slate was presented and supported by the Executive Committee and will be presented to the full Planning Council for approval at May 2011 meeting.

The Substance Use/Harm Reduction service guidance has generated much discussion and input from community members, principally around the Community Reinforcement Approach (CRA), which culminated in the decision by the Executive Committee to delay the issuance of the RFP and to send it back to the Integration of Care Committee for further analysis, examination and discussion.

Dr. Fabienne Laraque, Director of the Care, Treatment & Housing program, will be leaving the NYCDOHMH on May 6 to work in Haiti for the next two years. The Planning Council Support Unit will no longer report to the grantee, but rather to the Division of Disease Control, which will allow the Planning Council to maintain its independence.

HIV/AIDS TREATMENT UPDATES

Mark Milano of ACRIA (AIDS Community Research Initiative of America) presented an update on HIV treatment, reviewing the history of HIV, including the identification of HIV as the causative agent of AIDS, the approval of the HIV antibody test in 1985 and the early and widespread use of AZT (vs. placebo). The revised DHHS guidelines on when to initiate antiviral treatment, as well as HIV pathogenesis issues such as seeding, inflammation, lifecycle, the role of co-receptors, relationships between viral load and CD4s, recommendations for laboratory testing, developments in medication, including fusion and attachment inhibitors, medication dosing and pharmacokinetics, vaccine research, microbicides and PEP/PEP. Of particular interest to consumers are the recommendations for laboratory testing which include going to the same lab every time for consistency, going at the same time of the day, avoiding blood draws immediately after rigorous exercise, waiting three weeks after

infection or vaccination and getting sufficient sleep. Consumers were advised, before starting medications, to ask about the name of the drug, the rationale for the drug's use, how to take the drug, common, serious and long term side effects. Concerns regarding PREP include adherence, resistance, disinhibition, intermittent use, sharing of meds, financing of medication regimes and ADAP waiting lists. For more information, please refer to the meeting handouts or contact Mark Milano at ACRIA at mmilano@acria.org

HIV NETWORKING ACTIVITIES – BOROUGH UPDATES

Victor Benadava reported that the Staten Island CARE Network will be meeting on April 25 at the LGBT Center in Staten Island.

The Manhattan HIV CARE Network recently met at Sisterlink where Matthew Lesieur delivered a presentation on fiscal cutbacks.

The Brooklyn Network continues to meet and benefit from increased community participation.

PUBLIC COMMENT & ANNOUNCEMENTS:

Pastor Payne spoke to the details of the curtailment of Medicaid-funded home care services.

Gregory Cruz suggested that the Consumer Committee should begin to address the gaps in service and barriers to service for PLWHAs. Committee members were urged to actively participate in Planning Council activities, including the annual PSRA process, the 2011-13 Needs Assessment process and IOC discussions, particularly around the development of service directives.

ADJOURNMENT:

There being no further business, the meeting was adjourned at 4:00PM.