



CONSUMERS COMMITTEE

Wednesday, January 19, 2011 1:00 – 3:00PM

Hispanic Federation, 55 Exchange Place, 5th Fl. Conf Rm , New York, NY

Planning Council Members Present: Victor Benadava (Co-Chair), John A. Eddie (Co-Chair), Kareem Clemons, Gerald DeYounge, Yves Gebhardt (for E. Viera, Jr.), Alexander Hardman,

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

Community Members Present: Gregory Cruz (Consumer At-Large), Manuel Ducret III, Colombia Fierro, Stewart Fogel, Myron Gold, Mallory Marcus, Joseph Sellman, Escott Solomon, Michael Walker

DOHMH: Rafael Molina, Jan Carl Park, Nina Rothschild, Darryl Wong

MEETING MATERIALS DISTRIBUTED:

- Meeting Agenda;
- Planning Council Ground Rules of Respectful Engagement/Rules for Public Comment;
- December 15, 2010 Draft Meeting Minutes;
- Planning for Comprehensive Needs Assessment: What to Expect, Powerpoint NYCDOHMH presentation;
- NYSDOH Consumer Advisory Committee January 2011 News Brief;
- January 2011 Planning Council Calendar & Month At A Glance
- The End of AIDS? , ACRIA/ACHIEVE, Fall 2010

INTRODUCTIONS:

The Co-Chairs welcomed participants, John Anthony-Eddie led the moment of silence was observed and the meeting participants reviewed the Rules of Respectful Engagement.

Darryl Wong reviewed the meeting agenda and meeting materials. The minutes of the December 2010 meeting were reviewed and approved.

PUBLIC COMMENT:

Myron Gold circulated a petition urging passage of legislation to guarantee access to prescription drugs through local pharmacies in lieu of mail order pharmacies, some of which have been problematic for PLWHAs due to delivery problems. Stewart Fogel urged consumers to contact their local and Federal legislators as this would be a Federal policy change.

Gerald De Younge encouraged Committee members to participate in the Planning Council training series being conducted by the Leadership Training Institute (LTI).

Escott Solomon publicly thanked HIV Planning Council staff for their responsiveness to his agency's grant application request for supporting documents. He also noted that there is a dearth of female Committee participants and that recruitment should focus on this under-represented group.

Manuel Ducret announced that NYSDOH will be conducting Re-Designing Medicaid Forums in both the Bronx and Manhattan.

PLANNING COUNCIL UPDATES:

Jan Carl Park opened his Federal Policy update with the announcement that the Republican-led House of Representatives would be voting to repeal the Health Care Reform Act, which is largely symbolic in that it is not expected to pass the Senate (or be referred to the President). He emphasized that all consumers should be fluent in issues relating to their health care so that input may be provided when necessary.

The Federal government is operating on a continuing resolution for 2010, meaning that the Federal budget is still in place. It is not expected that there will be any increases in Ryan White funding and we do not know at this time the size of our award on March 1st for FY11. Speaker Boehner has indicated that he is seeking a reduction in programs like Ryan White by nearly 22%. Since Ryan White funds will expire in 2013 and those who are not Medicaid-eligible will become eligible for Medicaid in 2014, those who are accessing Ryan White services in 2013 would no longer need to access Ryan White services in 2014, with the exception of certain mental health, housing, legal and support services which would not be covered under Health Care Reform and will always be needed by some Ryan White clients.

With regard to Medicaid re-design, it was noted that there are thirty (30) members on the panel, with only one (1) consumer (HIV-) included in that panel. It is not known at this time what the proposed changes may be. However, local counties will no longer have control over the program as the State will retain control. It was emphasized that consumers impacted by these changes need to be a continuing part of this conversation; the Policy Committee of the Planning Council has been engaged in discussions with the State Advisory Body. New York City receives ~ \$2 billion per year supporting Medicaid programs for PWAs in comparison to the Planning Council which receives ~ \$100 million for PWAs. A statement will be developed by the Planning Council and submitted online to heighten awareness of the needs of PWAs. Nina Rothschild, NYCDOHMH Planning Council staff, added that Policy Committee Co-Chair Kali Lindsey stressed that funding cuts to health care services should be avoided and instead taken from administrative lines.

The website for submission of testimony is www.governor.ny.gov/medicaidredesign. The Manhattan forum will be on January 27, from 10AM-1PM at Baruch College and the Bronx forum will take place at Bronx Community College from 3-6Pm later that day. There is no pre-registration required.

The City budget has just been delivered and will be discussed in the near future.

Yves Gebhardt announced that NIH has been re-structured, noting that the ACTG will no longer focus on just HIV, but will incorporate other morbidities, signaling the move of HIV into the mainstream as a chronic condition.

Mr. Wong reviewed the Planning Council's meeting agenda for the month, noting that the PSRA Committee will be meeting to discuss possible funding scenario cuts to next year's award. He also provided a brief update on the CAB survey, noting the project continues to move forward into the test phase.

NEEDS ASSESSMENT UPDATE & PRESENTATION:

Dr. Rothschild and Mr. Wong provided an overview of the Needs Assessment 2012-13 process. Highlights of the presentation included the following background information:

What is Needs Assessment?

- Needs assessment (NA) is a systematic process to acquire an accurate, thorough picture of a system's strengths and weaknesses, in order to improve it and meet existing and future challenges.
- Last Ryan White (RW) Comprehensive Needs Assessment was completed in 2002
- RW Comprehensive Needs Assessment is:
 - An ongoing process
 - A partnership activity between the Planning Council, NYC DOHMH, WC DOH and the broader community
- Sets the stage for the planning process by identifying:
 - The needs of the community (both those in care and not in care)
 - The services available to meet those needs
 - The gaps between needs and services
- Identifies trends in outcomes and any emerging trends of concern
- Ensures resources are allocated properly
- Contributes to the update of the next Comprehensive Plan (2013-2016), in conjunction with progress updates on the existing Comprehensive Plan (2009-2012) and any other major factors, such as policy shifts

The role of the Needs Assessment Committee (NAC) is:

- To advocate for the interests and needs of people living with HIV/AIDS in the planning and evaluation of Part A services
- To ensure the empowerment and participation of people living with HIV/AIDS in the Part A planning process
- To guide the needs assessment process and provide feedback throughout
- To provide context to the gaps identified

The timeline of Needs Assessment activities is as follows:

- HAB recommends a two- or three-year needs assessment cycle
- Data collection, analysis and review will happen in waves and information will be shared with NAC as available
- Epidemiologic profile will be completed
 - Data will be updated throughout NA process as needed

The components of Needs Assessment include:

- Epidemiologic profile
- Assessment of service needs among affected populations
- Resource inventory
- Profile of provider capacity and capability
- Assessment of unmet need and service gaps

The epidemiologic profile

- Describes the current status of HIV/AIDS cases in the service area, overall and for subpopulations, and provides some understanding of how the epidemic may look in the future
- Documents trends in HIV/AIDS cases
- Identifies populations and geographic areas with severe need

- Helps anticipate future caseload
- Helps calculate unmet need
- Is updated annually with the most current data available

The data sources available in the needs assessment process include

- HIV Epi and Field Services Unit - Surveillance data
 - new and prevalent AIDS diagnoses
 - new and prevalent HIV diagnoses
- Mortality data
- Census data
- Medicaid data
- SPARCS data
- STD data
- CHAIN reports
- Medical Monitoring Project (MMP) reports

Populations of special interest include

- 1. Previously identified populations of special interest
 - 1. Women and young women of color
 - 2. MSM
 - 4. LGBT*
 - 5. PLWHA over 50
 - 6. Immigrants
 - 7. AOD populations*
- 2. Epidemiologic evidence
 - There exists an increase of 3% or greater in HIV/AIDS prevalence, new diagnoses or mortality, in a given subgroup, over the past 2 years
- 3. Known high risk groups (from literature, etc.)
 - Homeless
 - Formerly incarcerated

The HIV/AIDS Resource Inventory is a

- Joint effort of the Bureau of HIV/AIDS Prevention and Control aimed at describing current HIV services in the service area and providing a comprehensive picture of the continuum of care
- Timeline:
 - Late 2008: Planning process commenced
 - Summer 2010: Bureau of HIV/AIDS Directory Steering Committee formed
 - October 2010: Combined process with RW Comprehensive Needs Assessment efforts
 - Nov 2010 – Jan 2011: Finalize database & data collection tools
 - Jan – April 2011: Collect and enter data
 - April – June 2011: Develop resource inventory
 - July – August 2011: Disseminate inventory

Components of the Resource Inventory include

- Contact information
 - Name, address, directions, type of agency (i.e., community health center) telephone

- Project service area
 - Geographic area in which services are provided (i.e., Manhattan, Brooklyn, Queens, Bronx, Staten Island)
- Language(s) spoken
 - Spanish, Creole, Russian, French, African dialect(s), Chinese, Sign language, etc.
- Target populations served
 - MSM, LGBT/Q, Homeless, Persons > 50 years, Immigrants, Substance users, sex workers
- Resources
 - Fees & Payments: Ryan White Part A/B/C/D/F, Medicare, Medicaid, Fee for service, Sliding fee scale, ADAP
 - Estimate the number of clients who fall into the abovementioned categories
- Services provided
 - Types of services delivered: HIV Prevention & Education, Medical case management, Medical care, Substance abuse services, Mental health, Food & nutrition services, legal services, etc.
- Service capacity
 - Number of different individuals served in a year (both HIV-positive and HIV-negative)
 - Number of slots sets aside annually for HIV-positive (if any) = potential capacity
 - Number of clients with HIV that can be served at any one time for each service type

Unmet Need and Service Gaps are measured as follows:

- Unmet need calculations were performed using the HRSA definition and the BHIV definition to obtain a better estimate of unmet need
- CHAIN “Service Needs and Utilization” report
- Resource Inventory
- Consumer focus groups
- Return to Care Survey report
- Other suggestions?
 - Information that needs to be captured
 - Methods of capturing information
 - Where to capture needed information

The next steps involved in the Needs Assessment process include:

- Feedback from today’s meeting will be used to structure the Epi profile and develop plan to collect data on service needs and gaps
- Epi profile will be completed, trends and new populations of special interest identified and results will be shared with NAC
- Tools will be developed to capture information from consumers and providers based on input from the NAC
- Resource inventory will be administered to providers

BOROUGH UPDATES ON HIV NETWORKING ACTIVITIES

- Victor Benadava noted that Staten Island providers have offered logistical support for networking activities; the first meeting will be on January 24;

- Mr. Ducret announced that the former Manhattan HIV Care Network is meeting today at Sisterlink;
- Mr. Solomon announced that the Care Coordination Committee of the Network has met recently, but that the Consumer Involvement Committee of the former Network is less robust, due to limited leadership availability;
- Mr. Eddie added that participation and involvement is the responsibility of consumers and service providers;
- Mr. Gold noted that he has received commitments from FOPWA for the procurement of space, lunch & metrocards for meetings of the Manhattan Consumer Involvement Committee;
- Mr. DeYounge noted that the former Brooklyn HIV Care Network is still active (the last meeting was in December 2010), due to private support;
- There was concern that mailing lists of participants were not readily available;
- Mr. Benadava informed the Committee that these updates can occur on a regular basis in order to keep members informed and engaged;
- Manuel Rivera commended Mr. Benadava for keeping these networking opportunities on the forefront.

PUBLIC COMMENT:

Mr. Gold commented that during the recent snowstorms, accessibility for consumers was severely diminished. He also reminded members that not all PLWHAs are thriving, despite recent comments from some governmental representatives.

Mr. Benadava reminded the Committee that the LTI trainings are a valuable resource and should be utilized. He announced that on February 3, the Substance Use service guidance will be reviewed at 125 Worth Street, 3rd Fl.

Mr. Rivera announced that the PLWHA Advisory Group will meet on January 28 at Cicatelli Associates. He shared his opinion that issues of relevance to the AG should be discussed openly, in a cooperative spirit. He voiced his concern that the Committee application deadline should take into account the varying health status of potential applicants.

Mr. Gebhardt announced that there will be community dialog tonight on 116th St. around HIV/AIDS, the formerly incarcerated and communities of color organized by the Black Leadership Commission on AIDS.

Mr. Escott asked how transportation would be addressed from consumers who wish to engage in advocacy efforts in Albany.

Gregory Cruz announced the formation of the National Capacity Building Institute, which can be reached at www.hivcbi.org

Mr. DeYounge proposed that a meeting be convened for community leaders to discuss future directions in networking.

ADJOURNMENT:

There being no further business, the meeting was adjourned at 3:30PM.