



CONSUMERS COMMITTEE

Wednesday, September 21, 2011, 1-3:30PM

NYCDOHMH, Gotham Center, 42-09 28th Street, Room 22-12, Long Island City, NY

Planning Council Members Present: Victor Benadava (Co-Chair), Gregory Cruz (Co-Chair), Randall Bruce, Gerald DeYounge, Pastor Jerome Payne

Planning Council Members Absent: Felicia Carroll, John Eddie, Steve Hemraj, Munying Hunt, Deborah Marcano, Hilda Mateo

Community Members Present: Manuel Ducret III, Yves Gebhardt, Johnny Guaylupo, Alexander Hardman, Delores Henley, Ron Joyner, Joey Lopez, Mallory Lowenstein, David Martin, Jacqueline Williams

Staff: DOHMH: Stephanie Chamberlin, Rafael Molina, Alan Neaigus, Ph.D., Julie Lulek, Darryl Wong

Guest: Kristin White

MEETING MATERIALS DISTRIBUTED:

- Meeting Agenda/Planning Council Ground Rules of Respectful Engagement;
- September 21, 2011 Draft Meeting Minutes;
- Consumer Committee 2011-12 Committee Member listing;
- HRSA CARE Action: HIV & Social Media, June 2011;
- Planning Council By Laws (5/11);
- Ryan White Part A & B Funding History;
- Ryan White Part A & MAI Service Category Descriptions 2011-12;
- Glossary of Commonly-Used Terms & Abbreviations;
- Consumer Board Operations & Functioning Survey, Jan 2011;
- Advisory Board Survey for Consumer Members, March 2011;
- Ryan White Part A Agency Client Satisfaction Survey: Survey Tool Development 9/11;
- Medical Monitoring Project (MMP), Summary Results of 2007-8 clients, Neaigus, Lulek, Navejas & Raj-Singh, NYCDOHMH;
- Needs of HIV-Positive Women and Men Receiving Care in NYC, Kristin White, Columbia University/Alan Neaigus, NYCDOHMH, September 2011;
- Positive Voice, National Association of People with AIDS, Vol2, Issue 12, 9/12/11 & National Gay Men's HIV/AIDS Awareness Day Special Issue, 9/19/11;
- ADAP Watch List, NASTAD, September 2011;
- Poz Magazine, Sept 2011
- September 2011 HIV Planning Council Calendar

INTRODUCTIONS:

Gregory Cruz, newly appointed Committee Co-Chair opened the meeting, followed by Committee member introductions. Joey Lopez led the moment of silence and Mallory Lowenstein reviewed the Rules of Respectful Engagement. Mr. Cruz reviewed the meeting agenda and

Darryl Wong reviewed meeting materials. The minutes of the August 2011 meeting were reviewed and approved.

PUBLIC COMMENT:

Myron Gold, Committee member, was recently hospitalized and would appreciate contact with telephone call. There are many changes affecting the provision of and access to services and clients need to be aware of them.

PLANNING COUNCIL, FEDERAL/STATE & CITY HIV/AIDS POLICY UPDATES:

Darryl Wong, Staff Liaison to the Consumer Committee, provided an update on Planning Council activities, noting the election of Dorella Walters as Community Co-Chair and the appointment of John Anthony Eddie as Chair of the Rules & Membership Committee. Victor Benadava, Committee Co-Chair was a candidate in the Co-Chair election and was widely supported by many Planning Council members.

The NY EMA received notice of its award of \$121,208,099 in late August, representing an increase of \$119,493. The Planning Council conducted its annual orientation for newly-appointed members and the Year 22, FY 2012-13 draft application will be available for Planning Council member review on October 4-6 at NYCDOHMH headquarters.

At the local level, Mr. Wong provided an update on CAB Best Practices Survey, noting the significant number of agency and consumer members' responses. Mr. Lopez mentioned that Committee members can be very instrumental in helping to induce non-responsive agencies to participate in the survey.

PRESENTATION I: RYAN WHITE PART A CLIENT SATISFACTION SURVEY

Stephanie Chamberlin of the Research & Evaluation Unit of the Bureau of HIV/AIDS at NYCDOHMH began her presentation on the development of the survey tool by reviewing the purpose of the self-administered survey, which is to:

- Gain portfolio-wide information about the clients' experience of Ryan White Part A services,
- Analyze this information alongside other programmatic data sources, and
- Utilize this information to improve quality service provision by providing feedback to service providers and improving the Care Treatment and Housing Program's work and support for service providers.

For the purposes of the New York EMA Ryan White Part A Portfolio-wide Client Satisfaction Survey, satisfaction will be defined as follows:

- The extent to which a client feels/perceives that they have received some **benefit from their engagement with the services provided** (Outcomes -behavioral, clinical, and social).
- The **appropriateness of the service** provided in relation to the client's personal reality (e.g. language, culture, life situation).
- The extent to which a client had a **positive or negative experience** with the structural (e.g. administrative process, physical space) environment at the agency, the technical services (e.g. information, therapy, resources) received, and their interpersonal relationship (e.g. communication, friendliness, level of interaction) with the service providers.
- The **accessibility of the services** provided in relation to the required resources from the client and constraints that the client overcame to participate in the service (e.g. location, time, hours).

Consumers contributed that the client's educational level and sexual preference should be included in the umbrella of appropriateness and cultural sensitivity, provider technical competency and outcome evaluation, client input and feedback mechanisms, varying missions & service delivery approaches to a wide range of target populations of surveyed agencies, keeping observations to one's direct experience(s), should also be considered.

A total of 65 agencies with 81 contracts in a wide range of service categories, including mental health, supportive counseling and family stabilization, harm reduction, recovery readiness and relapse prevention, outpatient bridge medical care, medical case management, and legal services will be surveyed and will include all clients who come to these sites for services during the 4 -6 week data collection period. The remaining services in the EMA's portfolio are newer and will be surveyed in the future.

The timeline of the implementation of the survey is:

- Fall 2011: Data collection over ~6 weeks
- December 2011 – January 2012: Data entry
- January – April 2012: Data analysis and report writing, including assessments of reliability and validity (broken out by agency and service category)
- November –February 2012: Continual engagement with stakeholders to gain feedback on the tool and the survey implementation process in order to improve the survey for future implementation.

It was noted that this is a general survey to measure satisfaction across a range of services, which requires general language in order to be able to measure specific satisfaction themes across all service categories; no more than 15 "agree – disagree" questions, 2 open-ended questions, and 5 demographic questions (age, gender, etc.) will be included in order to help assure a high response rate.

Ms. Chamberlin reported that many existing, tested and valid surveys were used to guide the development of the current survey. A survey collection box will be placed at the program to collect completed surveys.

Consumers were asked for feedback to questions addressing general satisfaction, such as "My life has gotten better since I began coming to this agency", "My life is much better since I enrolled in this program", "My daily problems are easier to manage since I began coming here for services" or "My health has gotten better since I began coming to this agency."

With respect to maintenance in care, questions such as: "The services here have helped me go to my primary care doctor's appointments more often", "The services here have helped me go to my primary care doctor's appointments more often", "The services here help me keep appointments with my doctor" and "The staff helped me understand how regular visits with my primary care doctor would improve my health" are being considered.

Ms. Chamberlin asked that consumers' responses to the questions be submitted to her within a few days so that the questionnaire may be submitted to the NYCDOHMH Institutional Review Board (IRB) for approval.

PRESENTATION II: MEDICAL MONITORING PROJECT – SUMMARY RESULTS FROM MMP SURVEY OF PLWHAS RECEIVING CARE IN NYC IN 2007-2008

Ms. Julie Lulek, Dr. Alan Neaigus of the HIV Epidemiology & Field Services Program of the NYCDOHMH provided background on the project:

MMP is a national study of PLWHA receiving medical care for HIV and is conducted by the Centers for Disease Control and Prevention (CDC) with local partners. In the USA, at the end of 2006 there were an estimated 1.3m people living with HIV/AIDS (PLWHA) (MMWR, 2008). In NYC, at the end of 2009 there were an estimated 108,886 PLWHA (NYC DOHMH, 2010)

The objectives of MMP are to develop greater understanding of the health status and health-related needs of PLWHA, and their HIV transmission risk and prevention through the implementation of a data-driven project based on locally and nationally representative samples of HIV infected adults in care that can inform the development and planning of policy and programs for PLWHA, e.g. Ryan White CARE Act planning councils and consortia.

MMP is a multi-year (2005-open) project of US adults in outpatient care for HIV and is a cross-sectional design (snapshot vs. longitudinal study) and is an annual multi-stage probability sample.

Data is collected using two sources: (a) a computer-based structured interview, face-to-face by a trained interviewer and conducted in private and (b) medical record abstractions. Data is collected pertaining to clinical status, treatment adherence, service utilization, HIV-related service needs and health behaviors (health care utilization, sexual, drug use, prevention)

The analysis sample of 513 surveys was culled from over 800 facilities in 2007 and 752 in 2008; demographically, the participants were older than 40 years, male, Black or Hispanic and US born. 49% identified as heterosexual, 43% identified as homosexual/bisexual, over 50% had greater than HS education. Over 50% received income from government income programs and 96% had health insurance coverage. Blacks and Hispanics reported lower CD4 counts than whites and whites were more likely to have undetectable viral loads. Over 87% had received Antiretroviral treatment. Of those whose CD4 was less than 200, 27% reported missing doses; of those with undetectable viral loads, 58% reported missing doses and 81% reported never missing a dose. Emergency room and urgent care utilization was greatest among those who CD4s were less than 200.

While 87% reported receiving free condoms, only 32% had talked to an HIV counselor, only 23% had participated in group sessions. Almost 60% reported having neither spoken to an HIV counselor or having participated in a group HIV prevention session. This may indicate an unmet need for ongoing prevention interventions.

The limitations of the study are: data are based on self-report, stigmatized behaviors (e.g., sex and drug risk behaviors) may be underreported, cross-sectional design, thereby preventing a determination of causal relationships. In general, caution is required in making generalizations to all NYC HIV-infected patients receiving care for HIV because some facilities did not participate, there was a low response rate in patient sample and is comprised of un-weighted data from a complex survey design. Mr. Benadava stressed the importance of expanding the provider facility pool and Mr. Guaylupo noted the lack of younger people in the survey.

Ms. Kristin White, an MPH candidate from Columbia University Mailman School of Public Health delivered a presentation regarding the HIV-related **needs** of HIV-positive women and men receiving care in NYC. The objective of her study is to examine the relationship between gender and HIV-related needs, her hypothesis being that women may have more or different HIV-related needs than men.

With over 1 million HIV-positive individuals in the US, it is important to understand HIV/AIDS-specific quality of life concerns and needs, such as assistance with transportation and case management services. HIV-positive women.

About two-thirds of women have incomes less than \$10,000/year and half of HIV-positive women have children living in their homes. Due to these circumstances, women may have different HIV-

related needs than men, e.g., women are more likely to delay HIV care because of a lack of transportation and childcare.

Of the **513** HIV-positive individuals receiving care in NYC in 2007 and 2008 enrolled in MMP, 128 are women, 367 are men. Ten (10) transgenders were excluded from the study.

In attempting to determine if women more likely than men to need childcare services, the Odds Ratio (OR) was used to determine if the likelihood of an event is the same for two groups.

An OR > 1 would indicate that Women are more likely than men to need childcare, while an OR = 1 would indicate that there is no difference between men's and women's need for childcare and an OR < 1 indicates that women are less likely than men to need childcare.

With respect to HIV related needs, individuals were asked, in the last 12 months, if they needed assistance finding doctor, assistance finding dental services, mental health counseling, transportation assistance, childcare services, assistance finding food, assistance finding shelter, home health services, chore or homemaker services, general social services, adherence support services, education or information on HIV risk reduction and HIV/AIDS case management. They were also asked if they were able to get the needed service.

In the study, women and MSW tend to have lower education level, while white MSM have higher rates of education beyond high school. Education, as a proxy for SES (socio-economic status) was found to have the greatest effect of women need's in seeking home health services, chore or homemaker services and assistance finding shelter or housing. When attempting to assess HIV-related needs, it is essential to distinguish between MSW and MSM, possibly due to differences in socioeconomic status. The analysis showed that individuals reporting social services type needs were not having their needs met. Limitations of the study include the small female sample size and the lack of a direct measure of income. However, this is a representative sample of HIV-positive individuals receiving care in NYC which attempts to analyze detailed measures of HIV-related needs.

BOROUGH UPDATES ON HIV NETWORKING ACTIVITIES

Staten Island CARE Network will be meeting at the LGBT Victory Center on September 26 for a presentation by ACRIA on medication.

The Brooklyn Network did not meet in July.

[The remainder of the recording was not audible].

PUBLIC COMMENT

There was no public comment.

ADJOURNMENT:

There being no further business, the meeting was adjourned at 3:45PM.