



## **CONSUMERS COMMITTEE**

Thursday, February 20, 2013, 1-3 PM  
LGBT Community Services Center, 208 West 13<sup>th</sup> St, Rm 410  
New York, NY

**Planning Council Members Present:** Victor Benadava (Co-Chair), Randall Bruce (Consumer-At-Large), Felicia Carroll, Muying Hunt, David Martin

**Planning Council Members Absent:** Victor Alvarez (Tri-County), Lotus Blackman, Gregory Cruz (Co-Chair), Gerald DeYounge, Rev. Keith Holder, Deborah Marcano, Tracy Neil, Pastor Jerome Payne

**Appointed Community Members Present:** Billy Fields, Delores Henley, Glen Phillip, Joey Lopez, Ron Joyner, Yves Gebhardt

**NYCDOHMH:** Stephanie Chamberlin, Elena DiRosa, Rafael Molina, Jan Carl Park, Darryl Wong

### **MEETING MATERIALS DISTRIBUTED:**

- Meeting Agenda/Planning Council Ground Rules of Respectful Engagement;
- January 16, 2013 Draft Meeting Minutes;
- Letters of Recognition of Service to JoAnn Hilger;
- 2012 NY EMA Client Satisfaction Survey;
- Supportive Counseling Services- Client Satisfaction Survey;
- NYSDOH/AIDS Institute Sampling Guidelines;
- Medical Monitoring Project (MMP) 2010 Local Questionnaire – English version;
- Medical Monitoring Project (MMP) Protocol;
- Data Security & Confidential Guidelines for HIV, Viral Hepatitis, STD and TB Programs, Centers for Disease Control & Prevention;
- Consensus Statement on the Criminalization of HIV in the US, Positive Justice Project, February 2013
- S2189A-2013: An act to amend the penal law, the criminal procedure law and the correction law, in relation to criminalizing the reckless transmission of HIV/AIDS and to require testing for AIDS and HIV for certain persons, New York State Senate, 2/13/2013;
- HIV Criminalization: Are You at Risk, Powerpoint Presentation, The Center for HIV Law & Policy, January 28, 2013;
- Evaluating the Impact of Criminal Laws on HIV Risk Behavior, Journal of Law, Medicine & Ethics, 30 (2002): 239-253;
- NY HIV Planning Council February & March 2013 Meeting Calendars.

### **WELCOME & INTRODUCTIONS:**

Victor Benadava Co-Chair, opened the meeting beginning with the group review of the Rules of Respectful Engagement, followed by the review of the agenda and meeting materials by Darryl Wong. A moment of silence was observed in honor of JoAnn Hilger, Ryan White Grant Administrator at NYCDOHMH, who passed away on February 1, 2013.

### **PUBLIC COMMENT:**

There was no public comment.

## **2012 NY EMA CLIENT SATISFACTION SURVEY: PILOT FINDINGS**

*Stephanie Chamberlin and Elena DiRosa* of the Research & Evaluation Unit of the Bureau of HIV/AIDS Prevention & Control of the NYCDOHMH presented the findings from a portfolio-wide client satisfaction survey in the NY EMA. The discussion began with a comprehensive review of the survey process, which was initiated in February 2012.

### **The NYC EMA's Approach: Measuring client satisfaction across the RW Part A portfolio**

Client satisfaction was measured, based on client benefits, i.e., perceived behavioral, clinical and social outcomes, appropriateness of services, including language, culture and life situation, and quality of care, including structural, technical and interpersonal measures, and accessibility with respect to location, time and hours of operation.

In advancing the goals of the National HIV/AIDS Strategy, which seeks to improve health outcomes for people living with HIV, research has shown that higher satisfaction levels are related to maintaining more stable relationships with health care providers, complying more closely with medical advice and treatment and keeping appointments. Reducing HIV-related health disparities addresses both access and quality of care and advances a client-centered approach to evaluation. Achieving a more coordinated response ensures a consistent measurement of satisfaction across service categories and service sites

The purpose of the NYC EMA's Satisfaction Survey is to improve quality service delivered through feedback to stakeholders and service providers, to inform the Part A planning process and the Care, Treatment and Housing Program's technical assistance for service providers, to gain portfolio-wide information about the clients' experiences of Ryan White Part A services and to provide a more comprehensive picture of services by complementing other program monitoring and evaluation efforts.

### **The survey format:**

100 possible survey questions were culled from grantee (NYCDOHMH) surveys, NYSDOH/AIDS Institute surveys for case management, mental health and other services, the PACIC survey (Patients' Assessment for Care for Chronic Conditions), the PSQIII (the Patient Satisfaction Questionnaire) and the PSQ18 (short form), followed by a revision to 50 items. With stakeholder input, including Planning Council consumers', a 17-item satisfaction scale was developed, using a Likert scale (Strongly agree, agree, neutral, disagree and strongly disagree) to rate responses. Two (2) additional closed-end satisfaction items queried overall satisfaction and whether or not a client felt that s/he was treated poorly and two (2) open-ended questions asking how a service provider could increase satisfaction and inviting the client to share their experience were also included. The length of time a client had been receiving services and five (5) demographic questions asking about age, race/ethnicity, gender, education and borough of residence were also asked.

### **The survey sample:**

From a total of 195 Ryan White Part A contracts which were awarded to 112 agencies across the NY EMA, 65 agencies with 82 contracts in 5 service categories in NYC were included for the pilot survey. The service categories included care coordination (28), harm reduction (25), Mental health (12), legal services (11), and supportive counseling (6).

### **Data collection:**

Data was collected over six (6) weeks in February and March 2012. In order to assure anonymous and confidential data collection, secure boxes were placed at each agency. In addition, hard copy survey responses in English and Spanish were collected. There were no electronic responses. Response rates averaged 30% of active clients (overall) – with a range of 25% of care coordination clients to 36% for both harm reduction and supportive counseling clients.

### **Demographics:**

49% of those surveyed are Black/African American, 31% Hispanic/Latino, 8% White, 1% API, 3% multi-racial and 7% identifying as other. 56% were male, 39% female, 2% transgender and 4% other. Brooklyn

residents accounted for 32% of those surveyed, Bronx residents 29%, Manhattan 20% and 10% Queens, 4% Staten Island and 5% other. 41% had below a high school education while 59% had high school. 38% of clients had been receiving services for more than 2 years at the agency where they were surveyed and 24% from 1-2 years.

### **Findings: Perceived treatment and satisfaction**

Only 4% of those surveyed felt that they were treated poorly. By service category, 6% of harm reduction clients felt they were treated poorly, 4% of supportive counseling clients, 3% of care coordination clients, 2% of mental health clients and 1% of legal services clients. Of all clients who felt they were treated poorly, 52% received harm reduction services, 31% received care coordination services, 9% mental health services and 7% supportive counseling services.

Reasons for the perception of feeling treated poorly include drug and alcohol use (15%), race and age (13% each), sexual orientation (10%), immigration status and primary language (8% each) and gender (6%). 15% indicated other reasons and for 13% of clients, this response was missing.

Some qualitative responses to these questions include: “can’t be helped or seen”, “Haters”, “changes in therapist”, “My counselor was strange”, “group disrespect”, “Change from 2<sup>nd</sup> patient navigator to a 3<sup>rd</sup> patient navigator. I should have been contacted by management or by Dr. X about such changes and why” and “Being white I feel a lot of reverse discrimination.”

Preliminary findings indicate that on a 5 point scale, where 5 indicates greatest satisfaction, the mean was 4.22 with 89% of responding with scores of 3.5 or greater. In response to the question gaging overall satisfaction, on 6 point scale, the mean was 5.42, with 36% responding between 3.5 and 5 and 61% scoring between 5 and 6 (or 97% scoring from 3.5 to 6).

By service category, all scored at or above the mean except for harm reduction. Confidence in the provider was the characteristic receiving the highest rating (4.46/5) and wait time, transportation and sharing information about oneself received the lowest rating

### **Findings: Survey completion process**

While 75% of those surveyed did not receive help to complete the survey, 17% did. Those with a high school education or above were less likely to receive help completing the survey. There was no statistical relationship between missing questions and receiving help on the survey. On average, satisfaction scores for negatively-worded questions were statistically *lower* than for positively-worded questions. Those with *higher* education had statistically *higher* average satisfaction levels on the 17-item satisfaction scale.

### **Discussion: Lessons learned and limitations**

Limitations in the application of these preliminary findings include:

Only people who are currently engaged were measured, the difficulty in speaking to satisfaction with offsite services, findings may not be specific to Ryan White-funded services, findings are not generalizable beyond the service provider and service category, literacy, language and education barriers may have limited client feedback, e.g., negatively-worded questions, positive response bias, e.g. concern with losing services, the tool is still being tested and refined and the contextual and qualitative feedback is limited.

Other key findings include: the sample was demographically representative sample, there is a high level of satisfaction across service categories, there are differences in satisfaction by education level and education and literacy issues appear to be related to appropriate survey completion

### **Next steps:**

Moving forward, next steps were identified: the revision of the survey tool and testing it again with additional service categories, the utilization of existing service provider meetings to distribute survey

materials and provide trainings, the utilization of findings from other data sources (e.g. focus groups) to provide context for analyses and the pursuit of additional funding to further adapt the tool and collect data electronically.

**MEDICAL MONITORING PROJECT UPDATE (MMP)**

For reference, the recently-introduced bill, S2189A-2013 was included in the meeting packet. This bill calls for amending the penal law, the criminal procedure law and the correction law, in relation to criminalizing the reckless transmission of HIV/AIDS and to require testing for HIDS and HIV for certain persons.

The Medical Monitoring Project Protocol and the Data Security Guidelines, issued by CDC, were included in meeting packets so that consumers could articulate their concerns within the framework of the project protocol and security guidelines. Definitions of public health and non-public health use of data, surveillance vs. research (and Institutional Review Board (IRB) review) were explored.

**BOROUGH UPDATES: HIV NETWORKING ACTIVITIES/PUBLIC COMMENT/ANNOUNCEMENTS:  
ADJOURNMENT:**

There being no further business, the meeting was adjourned at 3:00PM.

