



## **Consumers Committee Meeting Minutes**

October 21, 2009 1:30 – 4:00PM

Housing Works, 57 Willoughby Street, Brooklyn, NY

**Members Present:** Victor Benadava (Co-Chair), John A. Eddie (Co-Chair), Brent Backofen, Felicia Carroll, Gerald DeYounge, Linder Ford, Myron Gold, Glen Phillip, Ed Viera, Jr.

**Members Absent:** Anthony Case, Gregory Cruz, Billy Fields, Keith Kaiman, Marcelo Soares, Escott Solomon

**Guests Present:** Eric Bartley, Ronald Brown, Jolette Jones, Ron Joyner, Mallory Marcus, Yvette Modica, Lionel Smith,

**DOHMH:** Rafael Molina, Jan Carl Park, Darryl Wong

### **Meeting Materials Distributed:**

- October 21, Meeting Agenda
- Rules of Respectful Engagement
- NY HIV Planning Council By-Laws, Article IX – Conflicts of Interest
- July 22, 2009 Consumers Committee Meeting Minutes
- At-Large Consumer Member 2009-10 Nominations Announcement
- Positions on Proposed Fixes for Ryan White Program Legislation, CAEAR Coalition, 10/20/09
- How a Bill Becomes a Law
- Congressional Briefing on HIV/AIDS and Aging from 10/7/09 event
- White House Office of National AIDS Policy (ONAP) - Call to Action Briefing
- National HIV/AIDS Strategy (NHAS)/Community Discussions Calendar
- Tips to Form Effective Community Testimony to Shape a Results-Oriented National HIV/AIDS Strategy, CHAMP
- Obtaining Advisory Input from Consumers of HIV/AIDS Health Care Facilities, 2004, NYS DOH/AI
- Consumer Involvement Survey: Preliminary Report & Findings, NYSDOH/AI, 3/04
- Prevent Influenza, Vol 8, No. 8, Health Bulletin, NYCDOHMH
- Novel H1N1 Influenza (Swine Flu) Information for Persons with HIV/AIDS, NYSDOH, 9/09
- What Adults with HIV Infection should Know About the Novel H1N1 Flu, CDC, 9/09
- HIV/AIDS & the Flu, CDC 9/09
- October 2009 Planning Council Calendar

## **WELCOME & INTRODUCTIONS**

Victor Benadava welcomed participants, followed by member and guest introductions. John Eddields led the moment of silence. Mr. Gold reviewed the Rules of Respectful Engagement and Darryl Wong reviewed the agenda and meeting materials.

The minutes from the June 17, 2009 meeting were reviewed and approved with minor changes noted. Article IX of the Planning Council's Bylaws addressing Conflict of Interest were referenced and discussed, calling attention to the distinction between voting on an entire group of service categories (allowed) and voting on specific service categories (not allowed) when an individual works for an agency that receives funding in that specific service category.

#### **HIV PLANNING COUNCIL UPDATES:**

Darryl Wong reported on the following activities:

- Discussion and debate of the health care reform bill is continuing nationally and is being informed by local discussions of Medicaid managed care and SNPs, as well as the Early Treatment of HIV Act (ETHA)
- The Senate Labor-HHS Subcommittee approved its FY 2010 Appropriations bill, followed by the Senate Appropriations Committee approving the measure with a commitment of \$663 million.
- There has not been any action in either the House or the Senate on a bill that would separately address the extension of Ryan White. However, an amendment was put forth that would have extended Ryan White for three years, with a sunset of September 30, 2012, that was subsequently withdrawn even with a one year extension having been proposed. Were a repeal of the sunset not to happen, there would still be a safety net provision to extend Ryan White programming for one year. Health care reform efforts continue to face delays that will force the debate beyond the August recess and close to the sunset date of September 30, 2009.
- State Senator Duane was successful in shepherding the passage of a bill which would cap the rent contribution for low income people living with AIDS at 30% of their income.
- The PSRA Committee voted to add \$600,000 to the Food & Nutrition Services category in the FY10 Spending Plan; the actual amount to be programmed will depend upon the amount of next year's award. Criteria used in priority setting which increased the ranking of this service category include Consumer Priority and Emerging Needs/Specific Gaps.
- The PLWHA Advisory Group's Resolution mandating PWA representation on Boards of Directors of agencies receiving Ryan White Part A funds was passed at the full Planning Council on June 18, 2009.

#### **2009 CONSUMER FOCUS GROUPS:**

Alexandra Duncan, consultant to the NYCDOHMH, presented the results of the 2009 consumer focus groups on behalf of Pedro Mateu-Gelabert, the facilitator of the focus group series. Her talk focused on an overview and history of the consumer focus groups, the methodologies utilized, the survey of service assessment and recommendations developed from the focus groups. Highlights of the Executive Summary include:

- In March and early April 2009, NYCDOHMH conducted 12 two hour focus groups, representing 125 consumers of HIV-related services from 38 different agencies;
- Focus groups were conducted in all 5 boroughs and included both mixed gender groups as well as particular affected populations, including women, transgender persons, older adults, new-releasees and those whose primary language is Spanish;
- Different steps involved in becoming an HIV patient;
- The value of addressing the client as a whole person;
- A critical view of eligibility criteria for certain services;
- Concerns about health insurance;
- Mixed experiences with case management;
- The importance of housing, ADAP and substance abuse services;
- The role of prompt service delivery, logistical supports and one stop shopping in increasing access to care;
- The perceived inconsistency of services by Borough;
- Limited knowledge of and participation in CABS; and
- Specific barriers experienced by populations addressed in the composition of these groups

The following recommendations were derived from focus group participants' suggestions:

- Provide guidance for the newly diagnosed;
  - Case management services could facilitate the process of acknowledging HIV status, as a first step toward accessing care.
  - A guide could be developed to help consumers “come to terms, navigate, and advocate” for services.
- Disseminate information regarding available HIV services;
  - This could be accomplished by using case managers and service providers as hubs for referrals and information on available services.
  - The aforementioned guide could help by including: explanations of common lab tests, definitions of HIV-related terms and a provider directory with detail on services.
- Clarify eligibility criteria for services;
  - Correct any misperceptions or actual provider practices that may function as disincentives for positive health behaviors.
- Aid consumers in navigating health coverage plans;
- Expand access to good-quality housing;
- Improve linkages with other services (e.g., thorough assessment of consumer needs, one case manager referring to multiple services, doctor’s office as hub for services);
- ADAP and housing also figured heavily in the quantitative survey results, as the services most often selected among respondents’ top three most important core and supportive services for remaining in primary care, and (in the case of housing) as the one most often selected among respondents’ top three supportive services for accessing primary care. The quantitative results differed, however, in their emphasis on mental health services, as the category second most often selected among the top three most important core services for access to care and for remaining in care;
- Provide a one-stop shopping model of care;
  - Caveat: There should still be the option to obtain HIV services at a multi-service agency that is not HIV-specific, so as not to be instantly identifiable as a PLWHA.
- Address needs in underserved areas like Staten Island;

- Provide culturally competent services tailored to the needs of special populations; and
- Increase CAB awareness among consumers and strengthen the role of CABs in improving services.

### **COMMUNITY ADVISORY BOARDS: Review of Materials and Survey**

Darryl Wong reviewed the NYCDOHMH language regarding contractual requirements for the implementation and operation of Community Advisory Groups (CAG) for all Ryan White subcontracts. The contractual language contains references to 1) the Master Contract between NYDOHMH (the grantee) and Public Health Solutions (the Master Contractor), 2) the Subcontractor agreement between Public Health Solutions (the Master Contractor) and the Ryan White-funded agency (the Sub-Contractor) and 3) the Subcontract Scope of Services describing CAG implementation.

Escott Solomon asked what the implications are for non-compliance and who, from the master contractor insures that CABs are in place. He made an anecdotal reference to a CAB that files minutes for meetings that did not take place. Ron Joyner suggested that penalties need to be enforced through corrective action plans, etc. Mr. Wong responded that the process to insure compliance is based on site visits where minutes are reviewed and that grievances are by definition a complaint-driven process. He suggested that creating language to be included in these contractual agreements that is more specific, definitive and time-specific would help create longer-term structural changes that can really impact the effectiveness of CABs.

Myron Gold sought clarification on the terminology being used: CABs have been synonymously defined as Client Advisory Boards, Consumer Advisory Boards and Community Advisory Boards, creating confusion and lack of consistency among providers and consumers. Mr. Wong defined the above terms using the NYSDOH/AI publication (8/06), "A Guide to Consumer Involvement – Improving the Quality of Ambulatory HIV Programs". Other comments included:

- How is "functional" defined? How do we measure quality? How do we define and measure eligibility, accountability, key program roles, i.e., who develops the agenda, which agency staff participates as the CAB coordinator, who performs internal reviews of produced documents, including minutes and recommendations?
- The need for written, established CAB Policies & Procedures, By-Laws or Terms of Reference, developed by CAB members, should be emphasized and enforced.
- What is a CAB and who does the CAB advise?
- There should be a representative from the CAB at the agency meeting where CAB feedback/input is reviewed in order to assure that voiced concerns are addressed, as well as internal and accessible documented monitoring to insure follow-through. Peers, paid through stipends, could be utilized to implement the above recommendation.
- Low turn-out can be attributed to the negative attitudes conferred to PWAs by CAB staff.

Mr. Wong suggested that a baseline assessment on the functionality of CABS should be undertaken, in order to collect evidence-based data, documenting the scope and magnitude of challenges facing CABs, from which recommendations can be made. The 2004 NYSDOH/AIDS Institute survey questionnaire and report on outcomes addressing the processes of consumer input for CABS was distributed at the June meeting for the Committee's use as a template/tool to collect baseline data for the Committee's work on the development and implementation of CAB guidelines. Gregory Cruz suggested using a rapid assessment process. Lacking further time to

critically analyze this template, the discussion will be continued in the Fall (members may also email comments to [dwong@health.nyc.gov](mailto:dwong@health.nyc.gov))

**Community Updates/Public Comment/New Business:** FACES NY will be convening a conference on August 19, 2009.

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