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Consumers Committee Workgroup Session

October 22, 2008, 1:30-4:00PM

Housing Works, 57 Willoughby Street, Brooklyn, NY

Members Present: Victor Benadava, Felicia Carroll, Anthony Case, Gregory Cruz, Gerald DeYounge, Manuel Ducret III, Billy Fields, Linder Ford, Yves Gebhardt, Myron Gold, Glen Phillip, Marcelo Soares

Members Absent: Brent Backofen, Terri Faulkner, Gonzalo Mercado, Juanita Owens, Alvin Perry, Escott Solomon, Edilberto Viera, Jr.

Guests Present: Daniel Alford, Ronald Brown, Charlene Hamiter, Brenda Hopkins, James Lavigni, Jesus Maldonado, Peter Samprey, Joseph Sellman, Carol Vaughn

DOHMH: Reggie Jackson, Bertha Joyner, Rafael Molina, Jan Carl Park, Anthony Santella, DrPh, Jessica Wahlstrom, April White, Darryl Wong (Consumers Committee Staff Liaison)

Meeting Materials Distributed:

- October 22, 2008 Consumers Committee Meeting Agenda
- June 18, 2008 Meeting Minutes
- HIV Planning Council 2007-8 Consumers Committee Survey
- NYSDOH Medicaid Managed Care Consumer Forum Handout
- CHAMP Post-Election Teleconference Announcement
- Election 2008: Health Care Reform & the Presidential Candidates, NEJM, 359:15, 10/9/08
- Smoking Among HIV Positive New Yorkers: Prevalence, Frequency & Opportunities for Cessation, AIDS Behavior
- A Call to Action: Strengthening the Response to HIV/AIDS and Viral Hepatitis in Latino Communities, National Alliance of State & Territorial AIDS Directors

- 1 ▪ NYSDOH Part B HIV Care Network Contact List
- 2 ▪ Semi-annual HIV Epidemiology Report

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4 **Welcome and Introductions:**

5 Jan Park, Governmental Co-Chair and Darryl Wong, DOHMH Consumers
6 Committee Staff Liaison welcomed participants; members and guests
7 introduced themselves.

8 Jan Part led the group with a moment of silence, noting the recent passing of
9 Sharon Perkins, who was most recently affiliated with Bailey House and
10 previously worked with Public Health Solutions (formerly MHRA) and a
11 steadfast ally of PLWHAs. Linder Ford reviewed the Rules of Respectful
12 Engagement and Darryl Wong reviewed the agenda and meeting materials for
13 the afternoon's meeting.

14 **Review of June 18, 2008 Minutes:**

15 The minutes from the June 18, 2008 were reviewed. The motion was made,
16 seconded and the minutes were accepted (by consensus).

17 **Planning Council Update: Jan Park & Darryl Wong**

18 *Membership of the 2008-9 Planning Council:* The Bureau of HIV/AIDS
19 Prevention & Control has not yet received notification from the Mayor's
20 Committee on Appointments on the proposed slate of candidates whom we are
21 recommending for appointment. The Consumers Committee does not have Co-
22 Chairs at this time.

23 *Consumers Committee Members Roles & Responsibilities,* as described in the
24 recently-revised Planning Council By-Laws, were reviewed. Members were
25 reminded of their responsibility to be fully engaged in the planning process, by
26 assuring representation (either by the member or the alternate who is chosen by
27 the member). At the next meeting, the Consumer at-large represented will be
28 elected.

29 *PWA Advisory Group:* Felicia Carroll was elected as Community Co-Chair;
30 upon appointment of Planning Council members, a Planning Council Co-Chair
31 will be elected.

1 **HIV Care Networks:** The HIV Care Networks are meeting in each of the (5)
2 Boroughs; participants are urged to contact the Network directly for updated
3 schedules and meeting venues. The structure of the Networks is standardized
4 throughout the City – with full Network and Executive/Steering Committee
5 meetings and the breakout committees (Consumer Involvement, Care
6 Coordination and Policy/Education) meeting on a monthly or quarterly
7 schedule. The Brooklyn HIV Care Network is scheduled to meet on October
8 23, Staten Island on the 24th and the Bronx Care Network on the 29th. The
9 necessity of participating in the planning process was underscored in order for
10 issues relevant to PWHAs to be brought to the table for full discussion and
11 follow-up.

12 **Meeting Minutes:** Members were reminded that minutes are not verbatim
13 transcripts, but rather are intended to capture the essence of the comment and to
14 summarize the action(s) taken.

15 **Discussion of the 2009-12 Comprehensive Strategic Plan: Anthony**
16 **Santella, DrPh & Jessica Wahlstrom**

17 Dr. Santella provided background on the EMA's Comprehensive Strategic Plan
18 and reviewed the handout accompanying his presentation. He noted that:

- 19 ▪ there is no discussion of HIV primary prevention strategies or
20 interventions;
- 21 ▪ there is no discussion of HOPWA;
- 22 ▪ there is no contract-specific data or discussion;
- 23 ▪ the existing plan (2005-8) is available on the website, www.nyhiv.org;
- 24 ▪ this plan is the NY EMA's plan and represents the collaboration of the
25 NY HIV Planning Council and the NYCDOHMH;
- 26 ▪ the plan is organized around (4) distinct areas focusing on: what is the
27 present system of care, what is our vision of an ideal system, how does
28 the system need to change to increase the availability of and accessibility
29 to core services and how will we evaluate our progress in meeting short
30 or long-term goals?
- 31 ▪ the Consumer Committee and the Advisory Group will focus its work on
32 Chapter 3 (Vision) and Chapter (4) Goals;
- 33 ▪ the discussion at this Committee meeting will focus on the vision and the
34 goals;

- 1 ▪ at the next Consumers Committee there will be discussion on Monitoring
- 2 Activities (Chapter 5) led by Mary Irvine, DrPH; and
- 3 ▪ a final draft for review will be available at the end of November for
- 4 Planning Council review.
- 5

6 **Discussion & Comments:**

- 7 ▪ In response to M. Gold’s inquiry regarding the use of the term HIV in
- 8 place of HIV/AIDS, it was clarified that HIV would include the
- 9 continuum from HIV through AIDS.
- 10 ▪ J. Lavigini remarked that there is a dearth of females involved in the
- 11 planning process and sought clarification as to whether DOHMH would
- 12 pay for HIV testing; Ryan White supplements Prevention’s HIV testing
- 13 efforts .
- 14 ▪ Dr. Santella reiterated the Draft vision as developed through Planning
- 15 Council and underscored that this comprehensive vision includes all
- 16 components, whether or not they are paid for Ryan White funding.
- 17 ▪ M. Soares noted the absence of percentage increases for the outcome
- 18 measures and recommended that the plan factor in current and projected
- 19 cuts in funding when addressing future programming issues.
- 20 ▪ Health indicators as they relate to outcomes will be discussed at the next
- 21 Consumers Committee meeting.
- 22 ▪ Significant health disparities between neighborhoods exist within more
- 23 broadly defined geographic areas, e.g., East Harlem & Central Harlem.
- 24 ▪ Outreach and access to community-level assessments is a valuable source
- 25 of data for the planning process.
- 26 ▪ Ryan White Planning Council staff liaison D. Wong will serve as a
- 27 conduit for feedback, studies and other information sources for use in the
- 28 development of the Plan.
- 29
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31 **Consumer Committee Updates:**

32 **CAB Survey/Focus Groups:**

33 V. Benadava reminded NYCDOHMH that there is a longstanding commitment
34 to the value of consumer input and made a motion that there be a CAB survey

1 performed in this planning cycle. Because of community dissatisfaction with
2 1) the existing CAB survey methodology, veracity and quality of responses and
3 other concerns regarding CAB infrastructure, policies and operating procedures
4 and guidelines and 2) the non-representative small sample size of the 2008
5 focus groups, there was a commitment made in February 2008 where it was
6 agreed that methods of consumer input – surveys, focus groups, etc. would be
7 revisited and discussed for possible implementation in 2009. It was suggested
8 that Public Health Solutions’ Community Advisory Group weigh in on the
9 Committee’s request for a listing of CAB coordinators at each Ryan White-
10 funded agency. M. Soares made a friendly amendment that the list of CABs be
11 made available. *By consensus, there was agreement and a re-commitment to*
12 *conduct a discussion during which this issue will be revisited.* G. Cruz
13 reminded the Committee that the CAB survey was originally conceived to
14 measure satisfaction levels and emphasized the need for consumers and CABs
15 in the planning process. He suggested that significant time be devoted to
16 reviewing the guiding, seminal principles of the community input process, past
17 successes, challenges, best practices and that consumers be included in this
18 dialogue. M. Soares asked for CHAIN reports on studies on non HIV/AIDS-
19 related deaths among PWAs and suicide/mental health issues. G. Cruz
20 volunteered to facilitate this discussion at a later date.

21 **Meeting Logistics:**

22 The use of different venues in boroughs across the City was discussed in
23 connection with goal of expanding the demographic reach of the Committee.
24 However, it was also gratefully acknowledged that Housing Works’ central
25 location in downtown Brooklyn has been a contributing factor to the
26 consistency of attendance at Committee meets. Other locations include the
27 Lesbian, Gay, Bisexual & Transgender Community Services Center, GMHC,
28 Cicatelli Associates and Cathedral St John the Divine and the Dempsey Center.

29 It was suggested that the meeting time should be kept to Wednesday afternoon
30 from 1:30-3:30PM. Mr. Wong will present the options for Northern, Central
31 and Lower Manhattan at the next meeting.

32 **Public Comment/New Business:**

33 Announcements for the elected Member at Large will be distributed at the next
34 meeting.

1 Sen. Clinton has introduced House Resolution (HR 427) which, if passed,
2 would make affordable housing, with a 30% rent cap, a key component of HIV
3 care; Committee members are asked to contact their local Federal
4 representatives for co-sponsorship of this resolution.

5 There being no further business, the meeting was adjourned.

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