

Consumer Committee Year End Report 2005 – 2006 Session

Presented to the
Ryan White Title I Boston EMA
HIV Health Services Planning Council

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Produced by



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**This report was prepared by the following 2005-2006
members of the Consumer Committee:**

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Charge and Mission of the Consumer Committee

Participation in the work of the Consumer Committee is outlined in the By-Laws of the Planning Council:

Membership to the Consumer Committee shall be limited to persons who self-identify as HIV+ and to the parents and/or guardians who self-identify as having HIV+ children under the age of 18. All Planning Council members who self-identify as HIV+ may elect to serve on the Consumer Committee. (Section 6.6.1 of the Ryan White Title I Planning Council By-Laws)

The mission of the Consumer Committee is found in the motion passed by the Consumer Committee in 1999:

The mission of the Consumer Committee (as approved by the Committee 4-8-99) is to ensure that people with HIV and/or AIDS are empowered, supported and encouraged to work on the full range of activities that the Planning Council undertakes in the execution of its mandate.

The objectives of the Consumer Committee are to:

- ❖ Foster and develop consumer leadership;
- ❖ Inform the Planning Council on issues from a consumer perspective, as needed; and
- ❖ Ensure that diverse consumer input is included in all Planning Council and committee activities.

The Year At A Glance

The Consumer Committee has devoted its efforts during the 2005-2006 session of the Planning Council to the following tasks:

- 1) Ensuring effective participation of Consumers on the Planning Council;
- 2) Fostering and developing Consumer leadership on the Planning Council;
- 3) Identifying, proposing and helping develop skills building trainings for Consumers on the Planning Council;
- 4) Informing the Planning Council on issues from a Consumer perspective as needed;
- 5) Ensuring that diverse Consumer input was included in all Planning Council and Committee activities, and
- 6) Providing input on the ADAP discussion.

A more lengthy description of the committee's work undertaken to achieve these tasks is given in the discussion to follow. The Consumer Committee met a total of nine times during the 2005-2006 session of the Planning Council, with two more meetings scheduled for the balance of the term. Each of these meetings had several elements to them:

- a reading of the charge to the committee;
- a review of the minutes from the preceding meeting;

- a review of the Planning Council agenda to prepare for the meeting and a discussion of particular items of the agenda;
- often an in-service training was offered by a member of the committee at which some aspects of the presenter's life, work and experiences were presented so as to educate other members of the Committee on the many aspects of living and working as an HIV+ person;
- several educational presentations were made to provide a deeper background on topics pertinent to consumer input at Planning Council meetings;
- several leadership skills trainings were offered by BAC staff to provide members with tools and skills to be more effective members and leaders of the Planning Council, at work and in their communities, including the topics of active listening and public speaking;
- a time for community concerns, for members to discuss what is happening in their communities and share ideas and suggestions.

Trainings

During the 2005-2006 session, the following training sessions were conducted:

- ❖ This session, trainings were provided on a one-to-one or one-to-two basis for members of the Consumer Committee who participated in the Laptop Program, as needed and requested by individual members. Most of this year's participants were familiar with using computers. Where a participant was just beginning to use computers, staff (E. Rewolinski and A. Hibbert) provided orientation and coaching. This session two applicants requested computer training in Spanish. Staff entered into discussions with the training staff at Latin American Health Institute to provide Spanish mediated training. Unfortunately, staff changes at the management level of the training department interrupted the plans. A subsequent move by the training center to a new location only prolonged the delay. Spanish-based training could not be provided. Support staff will attempt to alert LHI that the need for Spanish-based training remains as well as ongoing training in the most typically used software packages such as Microsoft Word.
- ❖ On November 30, 2005, Gaurav Bhattacharya, Project Manager, gave a training which several Consumer Committee members attended entitled: "*HIV/AIDS Epidemiology: Interpreting and Using HIV/AIDS Data.*" The objectives of the training were to assist Council members in understanding what epidemiology is, what it is used for and how the data is collected, used and presented to plan for HIV/AIDS services in the Boston EMA.
- ❖ This session, BAC staff also began an in-house Leadership training for the Consumer Committee, as requested by members in previous meetings. The goal of these trainings was to provide members with the tools and skills to be more effective members and leaders of the Council and in their communities. The first Leadership training on *Active Listening* was conducted by Andra Hibbert at the February

9th, 2006 Consumer Committee meeting. The second training on *Public Speaking* was led by Charlotte Kang at the March 9th, 2006 Consumer Committee meeting.

- ❖ Kyla Raynor, BAC Senior Project Manager, presented a training on March 23, 2006 entitled: *“Review of the 2006 Needs Assessment.”* The objectives of the training were to understand the purpose of a needs assessment, become familiar with the different types of public health data that are used in a needs assessment, understand how these data are used to identify the needs of people living with HIV/AIDS, and discuss the recent BAC needs assessment of PLWHA in the Boston EMA.
- ❖ On May 24, 2006 Charlotte Kang, Project Manager, and Edward Rewolinski, Executive Director, conducted the training *“Understanding Public Funding for HIV/AIDS Care and Support Services in the Boston EMA.”* The objectives of the training were to assist Council members to better understand various public funding sources for HIV/AIDS care in the Boston EMA and the general types of services they provide and to be better participants in the resources and allocations process of the Council.

Laptop Program

The laptop program provided laptop computers, printers, an AOL account and consumables to consumer members of the Planning Council in order to develop computer skills, communicate efficiently with other members of the Planning Council and the staff of the BAC and BPHC.

As noted above, E. Rewolinski provided orientation trainings for new participants in the program and Andra Hibbert provided follow up consultation to users. In terms of meeting the need for laptop computers, the seven Dell Inspiron 1150 were all deployed. Two older generation Dells were also lent out. Due to demand levels, the older generations of laptops did not have to be distributed this year.

Meeting Activities

During the course of the 2005-2006 session of the Planning Council, the Consumer Committee met and worked on several items of Planning Council business. The following details the content and work of the Committee meetings.

- ❖ On October 13, 2005, the Consumer Committee held its first formal meeting of the 2005-2006 session. At this meeting, the committee members reviewed the Year End Report of the Consumer Committee for the previous session (2004-2005). Minutes from the last meeting of the previous session were reviewed and accepted. BAC staff (Edward Rewolinski) gave an overview of what the Planning Council committees do. The meeting reviewed the agenda of the Planning Council meeting. The group discussed the election of a committee chair and vice-chair along with a discussion of what these officers do. Nominations for the posts were opened and, it was noted, would remain open until the next meeting of the Consumer Committee. The New Council Member Orientation Evaluation reports were reviewed. The committee discussed trainings, reviewing past trainings that had taken place and gathering input on needs and interest for future trainings. The committee members also discussed the mentor/protégé program.
- ❖ On November 10, 2005, the committee met. The minutes from the October 13th meeting were read and adopted. Officers of the Committee were elected: Sheila Doh was elected chair and Arthur Weeks was elected vice-chair. The Planning Council agenda for that day's meeting was reviewed, including the Comprehensive Plan and Medicaid and Medicare Part D. There was a time for community concerns, in which an announcement was made about World AIDS Day community events. An educational presentation was given by Kevin Cranston, Director of the AIDS Bureau, on the changes in the state consortia system and its implications for consumers.
- ❖ The Consumer Committee met on December 8, 2004. The minutes of the November meeting were reviewed and accepted. BAC staff walked members through the agenda for that day's Planning Council meeting. Some World AIDS Day members' experiences were shared during the time for community concerns. An educational presentation was given by Sandy Matava, from Suffolk University, on the "*Outcomes Evaluation Projects*," reviewing the highlights of the annual Health Outcomes report.
- ❖ At the January 12, 2006 meeting, Arthur Weeks started the meeting as the new chair of the committee, as Sheila Doh had resigned. The minutes from the December meeting were read and accepted. Nominations were opened for vice-chair, and Mario Matos was elected as the new vice-chair. The agenda for the Planning Council meeting was reviewed, and Steve Moran explained the Planning Committee's proposed changes for the Service Category Definitions. There was a discussion on ADAP (AIDS Drug Assistance Program), to present a Consumer Committee response to the Kevin Cranston's MA HDAP and Heather Hauck's NH ADAP presentations at the Planning Council meeting, which was presented by Mario Matos. A desire for leadership training was also expressed.
- ❖ The Consumer Committee met on February 9, 2006. The minutes of the January meeting were read and accepted. The agenda for that day's Planning Council meeting

was reviewed. Steve Moran explained the Service Category Definitions that would be presented at the Planning Council meeting for a later vote. Mario Matos gave an in-service presentation on the circumstances surrounding his diagnosis and treatment and the effects. BAC staff Andra Hibbert led a Leadership Skills Training on *Active Listening*.

- ❖ The committee met on the 9th of March. The minutes from the February meeting were read and accepted. BAC staff reviewed the agenda for the Planning Council meeting. The priority setting exercise tool was reviewed in preparation for the Planning Council meeting. Arthur Weeks gave an in-service presentation on his life experiences surrounding his HIV diagnosis. BAC staff Charlotte Kang led a Leadership Skills Training on *Public Speaking*.
- ❖ At the April 6th meeting of the Consumer Committee, Mario Matos served as chair. The minutes from the March meeting were read and accepted. The committee reviewed the agenda for the April 6th Council meeting, and reviewed the priority setting exercise vote that would be held later that day, the funding principles and the 'sweeps' recommendations as part of the R&A process. A community consumer was invited for a presentation to the committee, focusing on his struggles and experiences receiving HIV-related services.
- ❖ On April 27, 2006, the Consumer Committee met. The minutes from the April 6th meeting were read and accepted. BAC and BPHC staff reviewed the Planning Council agenda for that afternoon, including the 'sweeps' funding. Joe Carleo, AIDS Housing Corporation, gave an educational presentation on HOPWA funding in the Boston EMA. Ozzie Rivera gave an in-service presentation on his work in housing advocacy, HIV education and outreach in the Latino community and risk reduction counseling. During the time for community concerns, Mario informed the committee about a new program in his community called Members for Coordination, Iris Rivera announced a consumer leadership training on May 19th sponsored by AIDS Alliance in Washington, D.C., and Sandra Newton described her positive experiences participating in the RFP process.
- ❖ The Consumer Committee met on May 11, 2006. The Committee reviewed and approved the minutes of the April 27, 2006 meeting. The Committee also reviewed the Planning Council agenda for that day. The Committee then reviewed the session's activities for the Year End Report and discussed recommendations to include to present to the Council.
- ❖ There are two additional meetings for the balance of this session: one on June 8, 2006, for which an in-service presentation by Sandra Newton is scheduled, and the last on June 22, 2006.

Committee Recommendations

The Committee also discussed recommendations they would like to present to the Planning Council for next year's term:

- ❖ That the Laptop Program be continued, as it was instrumental in enabling the members to participate in their Council work.
- ❖ That more consideration should be given as to how to foster consumer participation and leadership, i.e. through continuation of the in-service presentations.
- ❖ That more effort should be made in reaching out to consumers in the community for recruitment to the Council and for raising awareness about Ryan White and the Planning Council (e.g. an outreach/recruitment event (breakfast/lunch) planned by the BPHC before the beginning of the Council term open to all consumers in the community consumers to raise awareness). The Committee would also like to encourage the consumers on next year's Planning Council to take more of a leadership role in recruitment to ensure a good number of new members and new consumers and to ensure a demographically representative mix.
- ❖ That there should be more opportunity for consumers to speak about consumer concerns at Planning Council meetings (versus solely at Consumer Committee meetings). Currently, this does not occur during the committee updates. This could be accomplished by:

Scheduling topical in-service presentations at the beginning of the term to complement the topics presented at the Planning Council meetings. This will give consumers a forum to discuss the topics ahead of time and come up with a few key points, concerns or questions that they feel are important to bring to the Council table, which could be voiced by the Committee chair or the in-service spokesperson during a time specifically set aside for this purpose after the Council presentation. For example, if a Council presentation is scheduled on the topic of housing for PLWHA, a consumer could lead an in-service presentation at the preceding Consumer Committee meeting on his/her experiences with housing as a person with HIV, followed by a discussion about housing within the Committee, which would be narrowed down to two or three key points, concerns or questions. These would be presented after the Council presentation on housing.