

Consumer Committee
2006-2007 Year-End Report
June 2007

Drafted for the
Boston Part A (Title I) EMA
HIV Health Services
Planning Council

Produced by



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*The Consumer Committee of the Boston EMA HIV Health Services Planning Council
presents its 2006-2007 Year-End Report*

Committee Charge

The Consumer Committee is one of the Planning Council's standing committees. The Planning Council's bylaws state the charge to the committee at Section 6.4.6:

“The Consumer Committee shall ensure that people living 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, by:

- A) Fostering and developing consumer leadership;
 - B) Working with the Executive Committee to ensure that at least one Consumer Committee member is on each Planning Council committee;
 - C) Informing the Planning Council on issues from a consumer perspective, as needed; and
 - D) Ensuring that diverse consumer input and participation are included in all Planning Council and committee activities.”
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Committee Membership

Members

Arthur Weeks, Chair
Sandra Newton, Vice-Chair
Osvaldo Rivera, Vice-Chair
Jorge Guzman
Mario Matos
Steve Moran
Iris Rivera
Constance Santiago
Van Thomas

Staff

Michael Hager, PCS
Jonathan Leite, PCS
Leela Strong, PCS
Kristin Elifson, BPHC
Raysheema Rainey, BPHC

Committee Meetings

Thursday, October 12, 2006	2:00pm-3:30pm	Boston AIDS Consortium
Thursday, November 9, 2006	2:00pm-3:30pm	Boston Public Library
Thursday, December 14, 2006	2:00pm-3:30pm	Boston Public Library
Thursday, January 11, 2007	2:00pm-3:30pm	Boston Public Library
Thursday, February 8, 2007	2:00pm-3:30pm	Boston Public Library
Thursday, March 8, 2007	2:00pm-3:30pm	Boston Public Library
Thursday, April 26, 2007	2:00pm-3:30pm	Boston Public Library
Thursday, May 10, 2007	2:00pm-3:30pm	Boston Public Library
Thursday, June 14, 2007	2:00pm-3:30pm	Boston Public Library
Thursday, June 28, 2007	2:00pm-3:30pm	Boston Public Library

Work of the Committee

Consumer Committee is unique among the Planning Council committees in that it has no assigned membership and its leadership is not selected by the Planning Council Chair. Instead, all Planning Council members living with HIV and parents with HIV-positive children are welcome to attend Consumer Committee meetings. The Chair and Vice-Chair are elected by the Consumer Committee members at their first meeting. Consumer Committee meets for ninety minutes before each Planning Council meeting.

Consumer Committee has two main functions. First, Consumer Committee acts as a place for Planning Council members living with HIV to preview Planning Council presentations. Second, Consumer Committee provides local people living with HIV a place to share their personal and community experience as it relates to Planning Council issues.

Consumer Training

Planning Council consumers were asked to assess their training needs through a survey at the beginning of the Planning Council term. Please refer to the appendix for a list of all available trainings. The following trainings were provided this Planning Council term:

- ✓ ***Epidemiology***
October 12, 2006
Assist Planning Council members in understanding basic epidemiological concepts including data sources, uses, collection and basic epidemiological terms.
- ✓ ***Needs Assessment and Using Public Health Data***
February 8, 2007
Assist Planning Council members in understanding the Needs Assessment process including; using public health data sources, data collecting and identifying the needs of people living with HIV/AIDS. An overview discussion of the most recent Needs Assessment was included in the training.
- ✓ ***Public Funding for HIV/AIDS Care and Support Services in the Boston EMA***
April 26, 2007
Assist Planning Council members in understanding various public funding sources for HIV/AIDS care in the Boston EMA and the types of services provided by these funding sources. Also assists members in understanding how Funding Streams data interplays with the Planning Council's Resource & Allocations process.
- ✓ ***Computer Skills Training***
Ongoing
Computer skills trainings were provided to participants in the Consumer Laptop Program (CLP) upon request. Most participants were familiar with computers. One applicant requested computer training in Spanish and one in English. PCS staff relied on in-house translators to provide the training in Spanish.

All training programs are being reviewed by PCS staff for updates and revisions over the summer interim.

Consumer Reimbursement Program

Consumer members of the Planning Council are eligible for reimbursement for certain expenses associated with their participation. These expenses include; childcare, parking, travel, and conferences.

Consumer Laptop Program (CLP)

CLP provided laptop computers, printers, an AOL account and technical assistance to consumer members of the Planning Council upon request. The CLP aims to provide an equal level of information access for all Planning Council members in addition to improving the line of communication between the Planning Council, PCS, and BPHC.

The CLP currently consists of thirteen laptop computers. Eleven of the machines were loaned to current Planning Council consumers and two additional laptop computers are available for use. Thirteen Planning Council consumers hold AOL accounts provided through CLP.

Liaison with Policy Committee

The Consumer Committee Chair Arthur Weeks worked with Policy Committee member and consumer Lester Payne and PCS to provide timely updates on pressing policy developments to the Consumer Committee. Consumer Committee conversation and questions related to these policy issues were then taken back to Policy Committee for answers and to provide a consumer-centered compass to Policy Committee research.

Consumer Committee Meeting Activities

✓ **Thursday, October 12, 2006**

The meeting included an assessment of Planning Council consumer training needs. Arthur Weeks was elected Chair of the Consumer Committee and Sandra Newton and Osvaldo Rivera were elected Vice-Chairs. The agenda for the October 12, 2007 Planning Council meeting was reviewed; the meeting's presentations were also reviewed.

✓ **Thursday, November 9, 2006**

The meeting included an assessment of Consumer Committee needs for the 2006-2007 Planning Council term. The agenda for the November 9, 2007 Planning Council meeting was reviewed; the meeting's presentations were also reviewed.

✓ **Thursday, December 14, 2006**

The agenda for the December 14, 2006 Planning Council meeting was reviewed; the meeting's presentations were also reviewed.

✓ **Thursday, January 11, 2007**

The agenda for the January 11, 2007 Planning Council meeting was reviewed; the meeting's presentations were also reviewed.

✓ **Thursday, February 8, 2007**

This was the first meeting with the Consumer and Policy Committee Liaison. The agenda for the February 8, 2007 Planning Council meeting was reviewed; the meeting's

presentations were also reviewed. Consumers developed a 'response' to the presentations provided by the Drug Reimbursement programs.

✓ **Thursday, March 8, 2007**

The agenda for the March 8, 2007 Planning Council meeting was reviewed; the meeting's presentations were also reviewed.

✓ **Thursday, April 26, 2007**

The agenda for the April 26, 2007 Planning Council meeting was reviewed; the meeting's presentations were also reviewed.

✓ **Thursday, May 10, 2007**

The agenda for the May 10, 2007 Planning Council meeting was reviewed; the meeting's presentations were also reviewed. Consumers developed recommendations for their 2006-2007 Year-End Report.

✓ **Thursday, June 14, 2007**

The agenda for the June 14, 2007 Planning Council meeting was reviewed; the meeting's presentations were also reviewed. Consumers drafted their Year-End Report.

✓ **Thursday, June 28, 2007**

The agenda for the June 28, 2007 Planning Council meeting was reviewed; the meeting's presentations were also reviewed.

Recommendations to the 2007-2008 Consumer Committee

1. Several members of the Consumer Committee have pointed out the benefits of standardized committee membership. For Consumer Committee to effectively serve as a marketplace for consumer ideas, it should have a group of five-six 'core' members assigned to it for consistency's sake. All other Planning Council consumers would still be invited to participate in the Consumer Committee dialogue. It is felt that membership standardization will also stabilize committee attendance.
2. Several members of the Consumer Committee request an expansion of cross-committee reporting along the lines of the Consumer and Policy Committee Liaison.
3. Several members of the Consumer Committee have pointed out the benefits of splitting the committee's two functions into two separate meetings. One meeting could remain at the current place and time and focus on the study-group function (this meeting would have no assigned members). Another meeting could be held on a different date to fulfill the information and experience sharing function (this meeting would have assigned members).
4. Consumer Committee members would like the study-group function to be supported by an understanding that materials will be available for review. It is acceptable that not all presenters will be able to appear at Consumer Committee, but it is essential that they provide advance copies of their presentations.
5. Consumer Committee members would like the information and experience sharing function to be supported by the personal stories of committee members. There were no new active Consumer Committee members this term and 2006-2007 members were already familiar with each others' stories, but there will be several new Planning Council consumers in the 2007-2008 term. Consumer-to-consumer presentations provide an anecdotal backdrop for conversations occurring at Planning Council.

6. The presentation and training principles suggested by the “Orsini Memo” should be adopted as a means of presentation continuity (*see appendix for memo text*).
7. Consumer Committee members appreciate the reimbursements provided as part of their participation on the Planning Council and recommend that this program be continued.
8. Consumer Committee members are grateful for the opportunity the CLP has provided, as it allows participants to engage in Planning Council work and the Consumer Committee recommends that this program be continued. CLP can be improved in the following ways:
 - a. the provision or reimbursement of high-speed internet connection to enhance communication between PCS, BPHC, and Planning Council consumers;
 - b. laminated handouts that explain precise machine capabilities and computer maintenance to assist those with less technology experience.

Appendix

Training Needs and Interests Survey

Survey Findings

HIV 101**[5 members interested]**

This training is designed to give participants an overview of basic virology as it applies to HIV prevention and treatment. Information on medications and recent scientific advances will also be covered.

HIV 102**[3 members interested]**

This training is designed to give participants an overview of political and social developments in treating HIV domestically and internationally. Updates from recent conferences will also be covered.

Epidemiology Part 1**[Mandatory training during Planning Council]**

This training is incorporated into the October 12, 2006 Planning Council meeting. It covers the basic terminology and application of epidemiology focusing on trends within the Title I Boston EMA.

Epidemiology Part 2**[3 members interested]**

This training is for members interested in advanced epidemiological study focusing on participants' ability to interpret and use data. Participants will practice the application of new skills through additional exercises and group activities.

Meeting Facilitation and Participation Skills**[3 members interested]**

This training is designed for members interested in improving their public speaking and leadership skills. Exercises include active listening, oral presentations, and active discussions on selected topics.

Hepatitis C and HIV Co-Infection**[3 members interested]**

This training focuses on the virology of Hepatitis C infection as it relates to HIV.

Needs Assessment and Using Public Health Data**[5 members interested]**

This training focuses on trends within the Boston EMA in terms of community needs, resource allocation, and available services.

Public Funding for HIV/AIDS Care and Support Services in the Boston EMA**[5 members interested]**

This training reviews the available funding for medical and HIV support services within the Title I Boston EMA. It includes federal, state, and city funding.

TO: PLANNING COUNCIL EXECUTIVE COMMITTEE
FROM: MARIA ORSINI, PLANNING COMMITTEE MEMBER
SUBJECT: SUGGESTIONS ABOUT PLANNING COUNCIL PROCEDURES RE: PRESENTATIONS
DATE: 2/7/2007

Greetings Executive Committee:

I have enjoyed my tenure at the Planning Council during these past few months. I really appreciate, respect and admire the work that current and previous members as well as Council Support Staff have done throughout the years. The intention of this memo is to share some thoughts and ideas on how to enhance the effectiveness of the yearly Planning Council presentations. As a new member of the Planning Council and as a professional trainer I want to offer some suggestions that could assist new members in settling into their new and important responsibilities.

I would recommend setting a standard for the presentations that are presented to Planning Council members. These presentations serve the purpose of informing members about the status of the variables that need to be considered when making decisions about how to best distribute Title I funds. Each presentation is a part of a big puzzle that all members need to be piecing together. However, from my experience as a Council member and as a trainer I know that sometimes it is hard to connect all of the dots, so to speak. Here are some thoughts that may assist in making this process more effective:

- 1) Set a format for presenters to follow. Presentations could include:
 - Presentation goals and objectives
 - Introductory slide that sets the context of the presentation (does this service or program receive Title I funds? Or is it run with funds from Title II etc.)
 - A slide or two that recaps the most important points presented. This way it will be clear to people what they should be getting out of each presentation.
- 2) Make presentations that are more user friendly. Presenters should use clear language that can be understood by different literacy levels. Doing exercises like the epidemiology exercise that was done at the beginning of the cycle year is an example of making complex information more accessible.
- 3) Until a new Needs Assessment is produced, Planning Council staff could come up with a list of two or three reports (and/or presentations) that members should quickly review prior to activities like the priority setting exercise. This can help in directing members to specific documents (two or three at the most) and perhaps even refer to specific sections that can facilitate the decision making process.

Please let me know if you have any questions. Thank you for your attention.

Maria Orsini
Planning Committee Member