

Consumer Committee Year End Report 2004 – 2005 Session

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

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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 are 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 2004-2005 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 Case Management Services 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 ten times during the 2004-2005 session of the Planning Council. 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 aspect 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; this year several educational presentations were made to provide a deeper background on topics pertinent to consumer input at Planning Council meetings.

Trainings

During the 2004-2005 the following training sessions were conducted:

- ❖ Throughout the 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. These trainings – “*Getting to Know Your Laptop*” – were conducted by the Executive Director, Edward Rewolinski. This mode of training was an experiment in tailoring sessions to the needs and learning styles of one or two individuals. Paige Eppenstein, Project Assistant, conducted follow up trainings on an as needed basis. While this method was time consuming up front, there appeared to be fewer problems for users after the trainings.
- ❖ On January 20, 2005, David Ayotte, Project Manager, gave a training which several Consumer Committee members attended entitled: “*HIV/AIDS Epidemiology: What it is, How to Make Sense of It, and How to Use It to Plan for HIV/AIDS Services in the Boston EMA.*”
- ❖ David Ayotte also presented a training in March, 2005 entitled: “*Review of the Needs Assessment and Using Public Health Data.*”
- ❖ On May 10, 2005 David 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 P. Eppenstein provided follow up consultation to users. An unexpected result of the program has been the *graduation* of several members from using Planning Council laptops to securing their own. This step indicated that members felt secure enough using internet and computer resources independently. Staff continues to provide assistance to those who have graduated out of the program.

Meeting Activities

During the course of the 2004-2005 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 14, 2004, the Consumer Committee held its first formal meeting of the 2004-2005 session. At this meeting, the committee members reviewed the Committee Report for the previous session (2003-2004) of the Consumer Committee. Minutes from the last meeting of the previous session were reviewed and accepted. BAC staff (Beth Hastie) gave an overview of what the Planning Council committees do; that after a new chair is elected, s/he would review the committee assignment preference forms and make determinations on what committees members would sit on. 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 committee members also discussed the mentor/protégé program.
- ❖ On November 18, 2004 the committee met. The minutes from the October 14th meeting were read and adopted. The Planning Council agenda for that day's meeting was reviewed. Sheila Doh give the first in-service presentation about her work at the Upham's Corner Health Center. Officers of the Committee were elected: Antonio Vasquez was elected chair and Sheila Doh was elected vice-chair. An educational presentation was given by Sandy Matava of Suffolk University on *Outcomes Measures for People Living with HIV*.
- ❖ The Consumer Committee met on December 9, 2004. The minutes of the October meeting were reviewed and accepted. BAC staff walked members through the agenda for that day's Planning Council meeting. An educational presentation was given by Jon Argenziano, Esq., Director, JRI Health Law Institute on *"MassHealth and Other Insurance Options for People Living with HIV."*
- ❖ At the January 13, 2005 meeting, the minutes from the November meeting were read and accepted. The agenda for the Planning Council meeting was reviewed. Heather Hauck, Section Director, NH STD/HIV Prevention Section, New Hampshire gave an educational presentation on New Hampshire's ADAP Drug Assistance Program. Steve Moran offered to make a Consumer Committee response to the New Hampshire presentation at the Planning Council meeting.
- ❖ The Consumer Committee met on February 24, 2005. The minutes of the January meeting were read and accepted. Ozzie Rivera gave an in-service presentation on what motivates his work, his history and his current job in helping formerly incarcerated persons living with HIV adapt to life outside of prison. The agenda for that day's Planning Council meeting was reviewed. Laurie Kunches, of JSI, gave an educational presentation in preparation for her talk at the Planning Council on clinical chart reviews of people served by Ryan White Title I funds. The committee reviewed and discussed the priority setting exercise tool and what would be happening at the

Planning Council around the setting of priorities. A discussion followed on the topic of zero funding certain categories of service. Steve Moran facilitated that discussion.

- ❖ In March, the committee met on the 10th. The minutes from the February meeting were read and accepted. BAC staff reviewed the agenda for the Planning Council meeting. Rich Stevens, Director of the AIDS Program at BPHC gave an educational presentation in preparation for the Planning Council meeting on the Fiscal Year 2005 award to the Boston EMA. The priority setting vote process and the zero funding vote process first brought up in the February meeting were reviewed again in preparation for action on them at the Planning Council meeting.
- ❖ On April 28, 2005, the Consumer Committee met. The minutes from the March meeting were read and accepted. BAC staff reviewed the Planning Council agenda for that afternoon. David Ayotte, Project Manager, gave an educational presentation on Ryan White Funding (all titles) for the Boston EMA. Steve Moran gave an in-service presentation on the work of the Resources and Allocations Committee which he chairs for this year.
- ❖ At the May 12, 2005 meeting of the Committee, Mario Matos served as chair. The Committee reviewed and approved the minutes of the April 14, 2005 meeting. The Committee also reviewed the Planning Council agenda for that day. Michael Goldrosen of the BPHC gave an educational presentation in preparation for the Planning Council meeting on Service Utilization. This preview came in two parts: 1) part one was on service utilization in the fiscal year 2004 broken out by modes of transmission, ethnicity, gender, etc. and 2) a second part which laid out the allocations of fiscal year 2005 dollars throughout the service categories and sub-categories. After the educational presentation, the topic of in-service training was raised. Julialene Johnson offered to make a presentation at the next Consumer Committee. E. Rewolinski mentioned that we would set up a training on meeting facilitation and PowerPoint.
- ❖ There are two additional meetings for the balance of this session: one on June 9, 2005 and the last on June 23, 2005. Julialene Johnson is scheduled to give an in-service presentation at the June 9th meeting. Ethan Herschman is scheduled to give an in-service on the 23rd.