

Meeting of the

Consumers Committee

November 16, 2004
Ryan Health Center 645 10th Ave
3pm-5pm

Minutes

Members present: L. Dolloway, K. Butler, F. Carroll, C. Craig, B. Curry, S. Hemraj, H. Mateo, Anthony R., D. Woodard

Members Absent: C., Cobb, C. Dzubilo, R. Gonzalez, J. Lopez, N. Nagy, H. Hernandez R. Gonzalez, J. Lopez, N. Nagy R. Abadia

Guests Present: J. Livigni, L. Holly, M. Gold, R. Joyner, And D. Chandler

Staff Present: I. Gonzalez, S. Bailous, and S. Dwyer

Agenda Item #1 Welcome /Introductions/Review Agenda & Minutes

L Dolloway, Co-Chair opened the meeting and had everyone introduce him or herself by sharing their background.

S. Bailous reviewed the meeting packet.

Lucille Dolloway led a moment of silence.

The agenda was approved as presented.

After review the Minutes of the October 19, 2004, meeting were accepted with the following corrections:

- Agenda Item #4 Public Comment- 2nd paragraph, 2nd sentence should read, “This will affect over 60,000 people with HIV.
- Agenda Item #5 Other Business- 1st paragraph, 1st sentence should read, “ It was announced that the Needs Assessment report that was distributed would be revised and updated.

Agenda Item #2 Public Comments

M. Gold stated that NYAC (New York AIDS Coalition) is putting together a PWA Caucus to discuss the importance of keeping PWA advocates involved. Special focus was on those PWA who were not re-appointed to the Planning Council as well as other advocates to ensure that these voices are not silenced. One of the ways that this will be accomplished will be through trainings to address specific issues.

J. Livigni stated that there was a conflict between the PPG meeting, which was being held on this date, and this meeting as members could not be at both. A request was made for meetings of PPG and PC to be scheduled in a manner that did not conflict with each

other. OAPC staff reminded members that they had no control over the PPG schedules and also encouraged members to bring up this issue at PPG meetings. Additionally members were reminded that due to holidays, November was a tough calendar month and as such there were more schedule conflicts between the two then usual.

HASA CAB-, which is proclaimed to be fully functional and yet nobody knows whom these people are or how they were selected. It is believed that there should be 11 members and that 6 of them should be PC members. As of this meeting it is unknown who these PC members that are on the CAB are. The Consumer Committee was urged to do something about it.

Agenda Item #3 Consumer Training for Planning Council (Nov 19)

Committee members were reminded of the upcoming training to be held on Friday November 19. Members were informed that Lenny Green will be the facilitator and he is a HRSA consultant who has worked with PLWHAs in our EMA in the past. This training will cover CARE Act Titles and will follow a similar track to the orientation held in September but will be more interactive.

During the public comment section the issue of how Planning Council Members are selected was raised. People were also concerned about the reasons for people not being selected and the perceived lack of clarity in how the selection process works. S. Hemraj brought up a discussion that the committee had started at the last meeting, which was using training for PWA as a way to select PC members. He proposed that an institution such as LTI (Leadership Training Institute) could be used to provide training to prospective PWA PC members. Those who completed certain courses would be given priorities when selecting new and continuing members. The committee did not come to a conclusion on this matter. However, Committee members had varying reactions to this proposal, they included:

- The concern that additional/extensive training would not be fair and could exclude potential leaders.
- The applications already ask about training.
- Limits participation to those that can take the courses.
- It's a form of discrimination- once you start discriminating- there is no end.
- PLWHAs are not the only ones that need training. Some providers do not know what's going on.
- The PC is already having a hard time attracting PLWHA.
- PWA training can be used as an incentive to join.
- Training should be offered year-round, but not mandated.

Agenda Item #4 Committee Participation/Assignments

Committee members shared their committee assignments with each other then voiced their concerns about PWA participation and the influence of the PLWHA and Consumers committee on decisions of the Planning Council. L. Dolloway shared that she already has a stack of folders and that it is difficult for her as a consumers to digest all the

information presented. B. Curry shared that this is true for other consumers as well and that more training and support is needed.

OAPC staff person, S. Dwyer explained to the Committee that at this point there is an understanding that all the work of the Planning Council's Committees will be shared with the Consumer's Committee before it is sent to the PC, although this language is not spelled out in the by-laws. Furthermore, each PC committee has at least 33% PWA participation, which allows for input from PLWHA during the development of committee work.

S. Hemraj made the following motion, which was unanimously accepted:
In order to ensure that there is real and meaningful participation from Consumers and PLWHAs time should be set aside for the consumer committee and the PLWHA advisory group to review the service model that will be developed by the Access to Care, Integration of Care and Maintenance in Care Committees.

Agenda Item #5 Planning Council Timeline

OAPC Staff person I. Gonzalez reviewed the Planning Council 3 year Planning Cycle timeline. The marked difference between this timeline and the one presented at the last meeting was discussed. Namely that this one looks at planning from a 3 year perspective as opposed to the last one which was focused on a year to year plan. It was also pointed out that this time line lists specific responsibilities for each committee of the PC.

Agenda Item #6 Other Business

Setting Agendas- a discussion was held around separating the work of the AG, the Internal/External Committee and the Consumer's Committee. Members expressed that at times it is disconcerting when they go from meeting to meeting and the same issue is being discussed. One such issue, which had been the subject of discussion earlier, was the HASA CAB. OAPC staff person S. Bailous informed the committee that it was decided that would be handled by the Internal/External Committee. It was agreed that in order to avoid duplication of work each committee should have its own responsibilities and that the Consumer Committee already has its set responsibilities, which are stipulated in the by-laws.

The discussion was then moved to the PLWHA Community Forums. Members expressed concerns about these forums not collecting consumer info per se, as many became a showcase for specific agencies. The Committee agreed that in order to ensure better consumer driven input, a better effort must take place to ensure that consumers attend with real issues and that locations are accessible in terms of transportation as well as accommodating for persons with immigration issues. Another suggestion was to have flyers translated into Spanish and Creole for the Latino and Haitian Communities.

Agenda Item #7 Announcements/Close

The next meeting will be December 14th 3-5pm.

The meeting adjourned at 5pm.