

Meeting of the

## Consumers Committee

December 14, 2004  
Ryan Health Center 645 10<sup>th</sup> Ave  
3pm-5pm

### Minutes

**Members present:** R Abadia, K. Butler, F. Carroll, C. Craig, S. Hemraj, A. Richardson

**Members Absent:** C., Cobb, C. Dzubilo, R. Gonzalez, J. Lopez, H. Hernandez R. Gonzalez, B Curry, H. Mateo, D. Woodard

**Guests Present:** J. Livigni, L. Holly, M. Gold, O. Clanton, B. Soskind, L. Gonzalez, O. Martin, and D. Chandler

**Staff Present:** I. Gonzalez, S. Bailous, R. Molina, and G. Moon

Agenda Item #1 Welcome /Introductions/Review Agenda & Minutes
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Rafael A., Co-Chair opened the meeting and had everyone introduce him or herself by sharing their background then reviewed the meeting packet.

Orbit C. led a moment of silence.

The Minutes of the November 16, 2004 meeting were reviewed and accepted as presented.

Agenda Item #2 Public Comments
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Myron G. stated that the AG and the Consumers Committee should collaborate on the HASA CAB issue, the changes in Medicare and Medicaid, and the outreach needed for the CAB survey.

Oliver M. asked that we formalize in writing the process for communicating to the AG the work of the consumers committee.

Agenda Item #3 Consumer Training for Planning Council (Nov 19, 2004)
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Orbit C. reported that he was one of the consumers who attended the training and he and the other attendees agree that the facilitator Lenny Green did a great job of explaining how consumers fit into the planning process. Anthony R. and Derrick C. agreed that they have a better understanding of the planning process from the training and look forward to the next training. Orbit C. added that this training should be repeated especially for new consumers coming into the process.

Rafael A. shared that another training is planned for 2005 that will continue the consumer training for Planning Council work. A training is being developed to teach basic

computer skills. Steve B. announced that the first Data Day, January 21, 2005, is a day of training and will focus on data that is needed to do the work of the council committees. The Needs Assessment committee will announce the location and agenda soon.

Rafael A. announced that the Policy Forum planned for February is important as we face Reauthorization. There will be busses going to Washington to make hill visits and training on policy issues is important before those visits.

Agenda Item #4 Committee Updates
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Derrick C. for Access to Care Committee reported that the committee is trying to iron out its charge. Ingrid G. added that there is a draft model on an HIV Care System that she will review with this committee later in the meeting. Anthony R. voiced a concern that he was the only consumer member present at the Integration of Care meeting. Rafael A. responded that Helen H. is also on that committee and promised to forward this concern as a concern from this committee and encouraged consumers to fill out the committee application for the positions that are open. Myron G. reported that the Needs Assessment Committee is planning Data Day and will be meeting via conference call to iron out details. Needs Assessment (NA) had a discussion on client level data. The NA committee responded to the concern that consumer comments should be included in the minutes and decided to be sure to include them. Rapid testing data collection is a concern as rapid testing becomes more common. The data specialists began to discuss what data they could provide for data day including information on delayed entry to care and who falls out of care.

Rafael A. reported that Priority Setting and Resource Allocation discussed services provided by other funding sources and the services by category. He reminded the committee that Hilda M. is one of the chairs of that committee. Rafael reported that Rules and Membership would be looking at member attendance and participation when it meets on next Monday. They are also reviewing the process to elect a new community co-chair as Noemi N. has resigned to move to Florida.

Derrick C. shared that the Internal/ External committee will be meeting to continue discussion on the HASA CAB, and Consumer outreach to CABS on December 17<sup>th</sup>.

The Committee Application is only open for membership on the Consumers Committee, Access to Care, and Maintenance in Care. Consumer participation is an issue that the council, and the Advisory Group have struggled with for a long time. Oliver M. stated that getting consumers involved will continue to be a challenge because consumers are not paid to participate. Oliver added that it would help if there was an orientation for consumers on the committees at the beginning of next years planning cycle. Steve H. suggested that the 33% participation requirement of the council be passed along to the committees. Steve B. shared that there is consumer membership on all the committees, but no pre-determined percentage. Steve said that the meetings are open for any interested persons to attend and consumers can have a presence and a voice at meetings even if they don't have a vote. The consumers who were appointed this year were selected from the pool of members from the old council workgroups and committees. The plan even with its flaws was to carry over the active participants from the previous structure to the new structure. Orbit C. suggested that we recommend an application

process for next year and that we reach out to AG members to apply. James L. noted that he has been at a number of meetings and has noticed that there is a shortage of PWAs at most of them.

#### Agenda Item #5 Reauthorization

Grace Moon reviewed the CARE Act 2005 Reauthorization Strategy that was developed by the CAEAR Coalition. The landscape is that the current administration is very conservative. There are key players who we will need to reach out to. Mike Leavitt the governor from Utah has been nominated to replace Tommy Thompson as secretary of Health and Human Services. AIDS activists are concerned because of Leavitt's history of cutting funds for Medicaid, which is the largest payer of HIV/AIDS treatment. Grassroots Strategy will include letter-writing campaigns and hill visits with a unified message. This will be a coordinated effort with local and national partners. The media will play an important part focusing on the stories of individuals and how the CARE Act has had and impact on their lives. The Reauthorization policy position from CAEAR and AIDS Action will be available in early January. Some of the issues of concern are abstinence only initiatives, harm reduction, and condom distribution programs. Congress is looking to pass the bill quickly without any major changes to the structure of the act. The OAPC can do training around the issues but can't do advocacy with Title I dollars. Grace reminded everyone to attend the Policy Forum in February. Ingrid added that the Care Networks are very involved in advocacy and sponsor training and buses to Washington.

#### Agenda Item #6 Other Business

Rafael A. reviewed the Community Co-chair Nominations notice in the meeting packet. The election will be at the January 20, 2005 Planning Council meeting.

FY 2004 reprogramming plan. MHRA approached food and nutrition programs, housing programs, and considered providing dignity kits for harm reduction programs. Of those contacted only the food and nutrition programs can use one-time enhancement dollars and the remaining funding will go to ADAP. Transportation and other program enhancements were not possible because of the short turn around and the need to spend the additional dollars by February 28<sup>th</sup>. Rafael A. shared that there is a need for food everywhere. Reprogramming dollars only go to existing contracts through MHRA that can spend the one time enhancement by February 28<sup>th</sup>.

Ingrid reviewed the draft Model for an HIV Care System and the questions to consider from the Integration of Care committee. The key to this model is the center section that shows how people move around in a circle of core services that maintain people in care. The third question, client pathways, sparked discussion. It was determined that the Prompts to Testing don't take into account individuals that are self-motivated. Steve H. shared that economic empowerment and its' impact on maintenance in care should be included. Ingrid responded that MIC looked at this as well, a little differently. MIC talked about the challenges for PWAs who have returned to work. It was noted that returning to work could cause people to fall out of care even though there are some services available evenings and weekends. It was recognized that there are a great number of people who get tested but do not access care. It was stated that returning to work is still difficult for

most PWAs. Ingrid shared that this discussion will continue at the Access to Care and the Maintenance in Care committee meetings on December 20<sup>th</sup> and 21<sup>st</sup>.

Agenda Item #7 Announcements/Close
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The Access to Care meeting will be at Ryan Center 1190 W 97<sup>th</sup> Street on December 20<sup>th</sup>.

The Planning Council meeting December will be at the LGBT Center and not in Queens.

The March on Washington planning committee in meeting and Derrick c promised to keep everyone informed.

The meeting adjourned at 5pm.