



Meeting of the

## HIV HEALTH AND HUMAN SERVICES PLANNING COUNCIL

January 20, 2005

3:15 – 5:10 PM

SEIU/Local 1199, 310 W. 43<sup>rd</sup> Street

### MINUTES

**Members Present:** S. Hemraj (Finance Officer), S. Abramowitz, PhD, K. Ashley, MD, P. Avitabile (for E. del Campo), M. Barnes, R. Bonilla, G. Brown, MD, K. Butler, E. Camhi, F. Carroll, E. Cates, R. Chavez, C. Cobb, C. Craig, B. L. Curry, L. Dolloway, C. Dzubilo, I. Feldman, L. Fraser, I. Gamble-Cobb, R. Gonzalez, J. Grimaldi, MD, M. L. Hernandez, J. Hilger, D. Marder, MD (for C. Barometre), H. Mateo, P. McGovern, J. Omi (for B. Chu, MD), T. Petro, P. Quintero (for M. Bacon), J. Pressley, A. Raiola, A. Richardson, C. Rivera (for A. Paige-Bowman), E. Santiago, E. Telzak, MD, T. Troia

**Members Absent:** H. Cruz, H. Hernandez, J. Lopez, D. Ng, W. Okoranyanwu, MD, T. Osubu, A. Palermo, J. Pedraza, B. Stackhouse, PhD, D. Woodard

**Staff Present:** *OAPC:* G. Moon, S. Dwyer, S. Bailous, C. Silva, I. Gonzalez, L. Fahie, R. Shiau, B. Barusek; *DOHMH:* J. Park, S. Forlenza, MD, MPH, F. Machlica; *MHRA:* R. Miller

---

#### Agenda Item #1: Welcome/Introductions/Minutes

*Mr. Hemraj:* Welcome to the first meeting of 2005, which will be a challenging year due to reauthorization.

*Mr. Cobb* led the Council in the moment of silence.

Ms. Moon reviewed the meeting packet.

The minutes of the December 16, 2004 meeting were approved with no changes.

Mr. Pressley reviewed the rules of respectful engagement.

#### Agenda Item #2: Public Comment, Part I

*D. Miller:* I want to bring to the Council's attention the critical issue of pulmonary hypertension among PLWHA. More and more PLWHA are being identified with advanced stages of this condition, and they are being excluded from clinical trials and there are no services for them. Care for people with pulmonary hypertension is extremely expensive, which makes it a Title I issue.

*M. Gold:* On January 1, 2006, changes will go into effect for dual Medicare/Medicaid recipients that will adversely affect PLWHA. I am in danger of losing access to home care and medications. The Council needs to address this issue. I have websites where you can get more information.

*L. Holley:* On February 2<sup>nd</sup>, grass roots organizations will converge on City hall to advocate for affordable housing. Everyone should be there as it affects every New Yorker.

*J. Livigni:* The new Medicare bill will not allow for lower cost re-importation of medication. Other rules hurt various populations.

### **Agenda Item #3: Committee Reports**

*Mr. Camhi:* Data Day is tomorrow. The Needs Assessment Committee has worked hard to set the agenda, which will focus on the way the Council is planning under its new structure – access to care and maintenance in care. The target audience is the Council and its committees, but it is open to all.

*Mr. Camhi (in response to a question from Mr. Feldman):* There will be a summary and copies of the packet for those who could not attend.

*Dr. Grimaldi:* After a lot of hard work, the Integration of Care Committee (IOC) has developed an HIV comprehensive care model, which will be presented at Data Day. It regroups the entire array of HIV services, including those not funded by Ryan White.

*Mr. Santiago:* I have been out due to pulmonary hypertension, but we encourage everyone to attend Data Day.

*Ms. Gonzalez:* The Access to Care Committee (ATC) has been looking at service categories and are looking forward to discussing the IOC model tomorrow.

*Ms. Cobb:* The Maintenance in Care Committee (MIC) developed a definition of maintenance in care, which was approved by IOC.

*Ms. Moon (in response to a question from Mr. Craig):* IOC is presenting its model to everyone tomorrow.

*Mr. Pressley:* The Priority Setting and Resource Allocation Committee (PS&RA) has been charged with developing scenarios for the spending plan should there be a reduction in the FY 2005 grant award. Potential scenarios include an across-the-board cut, holding particular services harmless (based on the Council's ranked priorities), doing a proportional cut in certain categories (again based on the Council's ranked priorities). PS&RA's recommendation will go to the Executive Committee (EC) in early February. The EC's recommendation will go to the full Council at the February meeting. We received a significant reduction in our HOPWA award this year, which may presage a similar cut in Title I. We expect the award notification by the end of February. It has been a difficult conversation, but thoughtful and has helped us look at ways to use data better to identify the best ways to use our resources.

*Ms. Mateo:* I was unable to make the last meeting as I was in Baltimore at a training of the AIDS Alliance for Children and Families on promoting access to care.

*Mr. Pressley (In response to a question from Dr. Abramowitz):* We did consider the principles developed for last year's scenario planning. We have to consider the Council's ranking, but there was some discussion on the committee that some categories are ranked too high. There was also agreement that no new RFP should be issued, and that we should look at take-downs for "poor performers".

*Mr. Barnes:* I have been in Africa starting HIV treatment programs for Harvard for several months and have not been able to make Policy Committee meetings. They are working on planning a public forum on reauthorization.

*Mr. Cobb:* Rules and Membership met to review applications for committee memberships. We made those recommendations to the Office of AIDS Policy Coordination.

*Mr. Hemraj:* The Finance Committee's next meeting is February 2<sup>nd</sup>.

*Ms. Carroll:* The PLWHA Advisory Group (AG) met on January 8<sup>th</sup>. The meeting started with a moment of silence, as is our tradition. This took on special meaning, as we had to once again remember one of our own, Cliff Mosley. We are going to have a memorial for Cliff in February and will announce the date and location soon.

We also shared updates on all the Council committees and encouraged members to attend tomorrow's Data Day. We discussed the AG's Community Advisory Board (CAB) Survey, which has just been mailed out. We are asking for your support for this effort. Please make sure consumers at your agency participate in the completion of this survey and return it by March 11<sup>th</sup>. AG members agreed to make sure the agencies they receive services from complete the survey. There will also be a phone effort to encourage every CAB to participate. We believe that last year's survey results helped the Council re-order its priorities and we want to ensure that consumer voices are heard again when it comes time to do priority setting.

Finally, on behalf of all the AG happy birthday to Mr. Abadia

*Ms. Dolloway:* The Consumers Committee welcomed Mr. Avitabile at its last meeting who announced that HASA is taking applications for its CAB as required by local law 49. He encouraged consumers to apply and explained the process and shared important information that is not included in the application, including that the appointments will be for two years, and that applicants will be investigated by the Department of Investigation.

The committee reviewed the CAB survey and agreed to work with the AG to ensure a good response. We see this as a great opportunity to collaborate on an important initiative for PLWHA. We also discussed Data Day and are looking forward to it and had a brief discussion on the Addendum to the Needs Assessment and plan to have a full discussion at next month's meeting.

#### **Agenda Item #4: Community Co-chair Election**

*Ms. Moon:* The personal statements from the two candidates, Mr. McGovern and Mr. Craig are in your packets. Only Council members or their alternates can vote.

*Mr. Craig:* When I tested positive with a diagnosis on full-blown AIDS in 1997, I knew very little. I joined a support group where I learned about the Division of AIDS Services (now HASA). I had gone to public assistance but they never told me about DAS. From my support group, I got more and more involved, joining a CAB and talking to patients in the hospital. I saw PLWHA not getting the care and support they needed and my program's funding cut. I became a treatment advocate and empowered myself, learning the medical jargon. Then I worked with Citiwide Harm Reduction as an outreach worker in SROs where I learned about IV drug use. I just finished working on a project on HIV prevention for SRO residents. I'm also a member of the NYC AIDS Housing Network. I'm in three boroughs a day and hear the concerns of the community, particularly housing. I want to get the community more involved in the Council, particularly with the need for PLWHA to advocate for reauthorization. I hope that I can be a worthy successor to Noemi Nagy.

*Mr. McGovern:* Firstly, I want to say that I'm familiar with Mr. Craig's advocacy and I would be proud to have him as our community co-chair. My bio shows that I have a broad perspective on services, which will be useful as we look at our service categories within our revised structure. To speak more personally about the passion that informs my work on this body, I am committed to ensuring that our processes are transparent and fair and that our decisions are driven by as complete and accurate data as possible. I want to ensure that our care system is responsive to the most vulnerable PLWHA. If we reach them, then we can be more confident that we are reaching everyone with HIV/AIDS. I would also work closely with the AG and Consumers Committee.

*Mr. Hemraj (in response to a question from Mr. Pressley):* The winner will serve out the remainder of Ms. Nagy's term (through September 2005), after which there will be another election for a full two-year term.

### **Agenda Item #5: Grantee Report**

*Ms. Hilger:* MHRA initially proposed \$1.3M in take-downs for agencies, which had an opportunity to appeal the amount with a plan for spending the funds by the end of the year. At the end of the process, MHRA took down 27 agencies for a total of \$552,000. 117 proposals were submitted in response to the RFP, and they are in the process of being reviewed. Legal Services, Supportive Counseling/Family Stabilization Services, and Treatment Adherence are being re-bid, plus there are three new categories in case of additional funding. Contract renewals in the re-bid categories will be for six months. All FY2005 contracts are being renewed and that process will conclude within the next month. Finally, many great applications were submitted for the MHRA CAG and the selection process should be completed soon.

*Ms. Miller (in response to a question from Mr. Pressley):* The dollar amount for the new categories in the RFP is about \$2M, should funding be available.

*Mr. Pressley (in answer to a question from Mr. Petro):* The PS&RA recommendation on RFPs was about new categories, for possibly reconsidering the ranking.

*Ms. Miller:* To clarify, the three new categories for which proposals were already received are for FY 2005 should there be additional funding.

*Mr. Pressley (in response to a question from Mr. Craig):* PS&RA discussed that we need to do our work using the rankings established in last year's process. However, some members expressed the concern that the rankings will need to be revised for the future to preserve the most essential services in case of a large cut.

*Ms. Mateo:* It will be a group effort among the committee members.

### **Agenda Item #6: Addendum to the Needs Assessment Update**

*Mr. McClain:* The Needs Assessment Update (NAU) includes documents from April 2002 through June 2004, which is the time since the initial Needs Assessment was done. There is a tremendous amount of data on HIV in New York and it is a challenge to keep up with it. The addendum includes additional documents through November 2004. The documents focus on critical issues to make it meaningful to you as planners. We focused on how service needs have changed and understanding the population not in care. There is a section on implications for and recommendations for planning. The addendum updates the epidemiological data and includes new information on community health. Thank you to Mr. Pressley for drawing our attention to the DOHMH community health profiles. We extracted both general and HIV-specific data from them that we thought would be useful for you.

*Ms. Gamble-Cobb:* Note that there are errors in matching ZIP codes and boroughs.

*Rev. Troia:* This is also true for the Staten Island data.

*Mr. McClain:* We will make the corrections.

*Ms. Moon:* Please submit corrections to the AIDS Policy Office.

*Mr. McClain:* We reviewed over 100 documents and we found that broadly speaking, the data is consistent with the 2002 Needs Assessment. While there may not be great shifts in the epidemic recently, there is evidence for improvement in the way you do priority setting and resource allocation.

*Dr. Lehrman:* Highlights of the new data include: the proportion of women and people over 50 with AIDS is increasing; there is a large number of delayed care seekers (up to 38%); the HRSA unmet need estimate for NYC is 32%; delayers often experience symptoms and are more likely to be substance users or have a history of unstable housing or incarceration; testing facilities that actively help get people into care are more successful at that; there are no demographic differences in the availability of or use of anti-retroviral

therapy; there are some gaps in services in various services (e.g. treatment adherence, mental health, housing), many of which have ripple effects on the use of other services. There is also some data from consumer studies showing the perception of gaps from PLWHA, and there is an appendix on data from the HIV QUAL data.

*Mr. McClain:* There are recommendations on the methodology for estimating unmet need, looking at where prevention and care goals overlap, addressing barriers that lead to delayed care and improving linkages to care. Thanks to the Council members and Office of AIDS Policy for their help on this project.

*Dr. Brown:* We should make sure that the data is all correct (ZIP codes, etc.) before disseminating this to the public.

*Mr. McClain:* It is a draft, and we can make those corrections easily.

*Mr. Camhi:* If we address delayed care seeking and bring more people into care, no one has made an assessment of our capacity to provide medical care. This should be addressed in the next assessment.

#### **Agenda Item #7: Public Comment, Part II**

*G. Huang-Cruz:* Cicitelli Associates and the Leadership Training Institute is conducting HIV and Mental Health Forums.

*R. Jones:* The NAU was very useful and the Council should consider the recommendations. Also, the AG and Consumer Committee are working to get more PLWHA involved in planning and the Council should support these efforts more.

*D. Miller:* There are critical gaps in the NAU. We need to look at holistic care, e.g. AETC programs.

*L. Holley:* Agencies should send their representatives to housing specialist meetings.

*J. Lavigni:* We should not rely on old data.

#### **Agenda Item #8: New Business**

*Ms. Moon:* Thank you to Mr. Craig and Mr. McGovern for volunteering to take on the hugely demanding role of community co-chair. Congratulations to Mr. McGovern on his election.

*Mr. Park:* Mr. Dwyer is leaving the staff of the AIDS Policy Office and I want to thank him for his tireless advocate for PLWHA.

There being no further business, the meeting was adjourned.

Minutes approved by the HIV Planning Council on February 17, 2005

---

Bill Stackhouse, Ph.D.  
Acting Governmental Co-chair