Meeting of the

EXECUTIVE COMMITTEE

Thursday, June 3, 2004
2:15-4:30pm
Friend's House, 230 E. 25th Street

M I N U T E S

Members Attending: R. Cordero (for F. Oldham, Jr., Governmental Co-chair), N. Nagy (Community Co-chair), S. Abramowitz, PhD, M. Barnes, C. Cobb, B. L. Curry, S. Halperin, CSW, M. Hill, PhD, D. Ng, T. Petro, J. Pressley, T. Troia

Members Absent: R. Abadia, G. Brown, MD, R. Chavez, H. Cruz, S. Hemraj, H. Melore, E. Santiago, P. Stabile, M. Wainberg, MD

Staff Attending: *OAPC:* D. Klotz, S. Dwyer, G. Moon, C. Silva, I. Gonzalez, R. Molina, M. Lesieur, R. Shiau, B. Cohen-Barusek; *DOHMH:* J. Hilger; *MHRA:* J. Verdino

Agenda Item #1: Welcome/Minutes/Announcements

Ms. Nagy opened the meeting.

Mr. Cordero reviewed the meeting packet.

Mr. Petro introduced the moment of silence.

Ms. Nagy: The next major steps in the priority setting process for fiscal year 2005 planning are: presentation of the reassessed templates to the Planning and Evaluation (P&E) Committee, with the P&E voting on all workgroup templates on June 25th. The Executive Committee (EC) will review and vote on priorities and resource allocations at its July 1st meeting. The full Planning Council will vote on final priorities and resource allocations at its July 15th meeting. If necessary, we have tentatively scheduled an additional Planning Council meeting on July 29th if necessary. It is very important that we continue to stick to this timeline.

Today, preliminary recommendations from the By-laws Task Force on restructuring of the Planning Council will be presented for discussion. The expectation is to provide suggestions and feedback regarding the proposed new committee structure at today's meeting. EC members may also submit suggestions to the By-laws Task Force via Mr. Dwyer by Monday, June 14th. Needs assessment is a critical part of our priority-setting process. Matthew McClain is unable to present today due to illness, but Mr. Cordero will provide a brief overview of our updated needs assessment, which includes unmet need. We expect to have a final outline of the 2004 needs assessment available for the June 17th planning council meeting. Mr. Barnes, who was a member of the Institute of Medicine (IOM) Committee that drafted the report on financing HIV care, will provide a brief summary on the, which has implications for the reauthorized Ryan White CARE Act. Workgroup and Committee chairs will then present brief updates on behalf of their committees, with a focus on fiscal year 2005 priority setting and reassessment of the workgroup templates.

Agenda Item #2: Public Comment

M. Gold: There is a conference this Saturday for faith communities on issues such as HIV and homelessness, and a SAGE conference on LGBT aging next week. An issue came up at the Village Center for Care CAB on disclosure. It is disturbing that PLWH still are afraid to disclose their status. We need more mental health services to help people cope with disclosure.

R. Joyner: There is a disparity in the ways that HASA approves housing for people of color. I have heard from case managers that HASA approves housing subsidies more readily in some HASA centers than others. I have asked Deputy Commissioner Del Campo to look into it.

Agenda Item #3: By-laws Task Force

Mr. Dwyer: The Planning Council's by-laws and structure have not been substantially updated since their inception in 1991. to ensure compliance with the CARE Act and responsiveness to local needs, the Planning Council began a comprehensive reassessment, starting with a joint working session of the Executive (EC) and Rules and Membership (R&M) Committees in August 2003. a By-laws Task Force was then created with 11 Planning Council members and our wise and patient consultant, Emily Gantz McKay. The Task Force met through May 2004, including meeting with HRSA project officer Sheila McCarthy.

The highlights of the proposed committee structure are: the PWA/HIV Advisory Group, R&M, Finance and Policy Committees will stay as is; the Data Committee will be beefed up into a Needs Assessment Committee (duties include: manage all aspects of data gathering and analysis, assess effectiveness of funded services in addressing Planning Council's priorities and allocations); a Care Integration Committee that will overcome the "silo" effect of planning in groups of discrete categories (this committee will oversee the six content-specific workgroups); a Consumers Committee of non-aligned PLAH full Planning Council members to oversee efforts to ensure meaningful involvement of PLWH in the Planning Council; and a Priority Setting and Resource Allocation Committee to fulfill those CARE Act mandates. The Executive Committee would lose its CARE Act legislative mandates and provide broad oversight of the Planning Council's business. Membership on all committees is described.

Mr. Dwyer (in response to a question from Mr. Halperin): The next steps are: please submit comments to the Task Force by June 14th. This will be presented to the full Planning Council at the June 17th meeting with a comment period. There will be a final vote on the new structure at the July 15th Planning Council meeting. The Task Force will reconvene in the fall to work on the other details of the by-laws, such as voting procedures. This is an ongoing process, and this portion only addresses article 6 of the current by-laws.

Mr. Halperin: This is a big step, and the Planning Council needs more back-up and detail, otherwise there is a risk of confusion. It should all be presented all at once.

Ms. Nagy: This is an opportunity to present what we have so far. The EC will have opportunity to submit revisions and suggestions before June 14th.

Dr. Abramowitz: The idea of the Integration of Care Committee is a brilliant move, but we need to make the workgroups more closely approximate the actual delivery of care. For example, does it make sense to separate primary care and mental health care?

Mr. Cordero: In addition to that, maybe we can integrate non-clinical services (i.e., AOD and social services), which we have already one at the staff support level, with Ms. Gonzalez, a CSW.

Mr. Pressley: I agree with Dr. Abramowitz. We also need a mechanism to see at end of the year how the new structure is working. There was no intermediary assessment of the current process.

Mr. Halperin: Perhaps we can have a "sunset clause" – try the new structure for one year, and then the Planning Council has to elect to continue it, to revise it, or to start over. I also support Dr. Abramowitz's suggestion, but it should be phased in slowly. This is a major change. We should leave the current workgroup structure for now, but vote to move toward integration during the year, otherwise we could lose continuity.

Ms. Verdino: Did the Task Force give any thought to organizing the workgroups like the spending plan, i.e. Physical and Life Sustaining Services, Targeted Services, etc. This would be consistent with HRSA's emphasis on access/maintenance in care.

Mr. Halperin: We did consider that at first, but decided to look at it later.

Mr. Ng: This structure calls for more person power from Planning Council members. We already do not have great participation by members on committees and workgroups. We would have to demand that they attend or remove them for people who will.

Ms. Curry: Thank you to Mr. Dwyer for his hard work supporting the Task Force.

Mr. Cordero: The proposed committees are pretty large. Perhaps the Task Force should look at smaller committees to address Mr. Ng's concerns. We do not want to burn out members. For example, the Social Services and AOD Workgroups met together once this year. We can formalize that and do it more often, while giving workgroups time to work on their own ideas.

Mr. Halperin: I worry about minority viewpoints from the community not being able to get on the table in an integrated system. That is the strength of the current workgroup structure.

Rev. Troia: We did try to group service categories, which is how the Integration of Care Committee was formed, but we can further examine integrating the workgroups.

Mr. Petro: I appreciate the work done, but it looks like, rather than a tighter structure, that it has expanded. People power is an issue, and also this will necessitate more meetings. There will also be a lot of overlap and will draw on and drain a smaller group of people. Maybe we should do a presentation to the full Planning Council and give them time to digest and discuss it before drawing up detailed by-laws. Also, we need to clarify decision making.

Mr. Halperin: This impacts the community. We should send the proposal to the public and have a public comment period.

Ms. Nagy: This was just a presentation of the overview. All the comments and suggestions today will be integrated into the process.

Mr. Cordero: To review the process: revisions from EC members are due June 14. We will present this to the Planning Council with a list of all suggestions on June 17th. Then, the full Planning Council will have a similar comment period. We will post it on the web site and inform the community. We will present further comments at the July 1st EC meeting. We can make changes at that EC meeting as a working session and vote so that the full Planning Council can vote on it on July 15th.

Mr. Halperin: There should be a public forum, especially so that workgroup members can comment. That will be more transparent.

Mr. Cordero: We have the New York Academy of Medicine reserved for the July 16th event on coordination with federal partners. We can add a public forum to that, then have the Planning Council review it on July 29th. [There was a consensus to accept that.]

The minutes of the April 1, 2004 meeting were approved, with Mr. Petro's absence noted.

The minutes of the May 13, 2004 meetings were approved with no changes.

Agenda Item #4: Needs Assessment Update

Mr. Cordero: I am presenting on behalf of Matthew McClain, who is unable to attend today due to illness. The tasks of the needs assessment update (NAU) are: to create an update to the 2002 Needs Assessment for New York

City, and to complete a mid-term EMA-wide review of Strategic Plan objectives. Evidence in both documents exists to make changes and improvements through priority setting and resource allocations. The focus will be on: how service needs have changed since the 2002 Needs Assessment, and the relevance of these findings to those "not in care" with a particular focus on "at risk" populations. The NAU will include: updated epidemiological data focusing on new information since 2002; "unmet needs" findings; other changes by workgroups since 2002; and implications and recommendations for planning.

The NAU team has met with key informants from Planning Council, CHAIN, AIDS Institute, and NYCDOHMH (4/2); attended the OAPC staff retreat (4/8) and Data Day (4/16); abstracted about 80 documents; submitted an extended NAU outline to OAPC and received OAPC comments (5/10-17); incrementally gathered feedback from key informants; continued developing the NAU draft using available data; and had an ongoing dialogue with key informants and OAPC.

After today, we will present the NAU summary and preliminary draft to the Planning Council and gather verbal input (6/17); submit a draft NAU (reflecting Planning Council input) to OAPC (6/28); distribute the draft NAU to the Planning Council (6/30); have a PC informant comment period and integrate comments into the final NAU (7/1-14); have a final presentation on the NAU to the full Planning Council (7/15); and distribute it following approvals.

Agenda Item #5: Institute of Medicine Report

Mr. Barnes: The Institute of Medicine (IOM) is an independent, quasi-governmental agency that Congress uses to study legislative issues. Congress commissioned the IOM to develop a report on the CARE Act and the financing of HIV care for low income PWLHA with the goal of recommending changes that would increase access to quality care and extend lives. The IOM Committee disqualified CARE Act grantees and others directly involved, and so the Committee was heavily made up of health policy experts. Issues identified in the report include: there is still no unduplicated client count, significant disparities exist in access to and quality of care, the current patchwork of public programs (Medicaid, Medicare, etc.) results in many PLWHAs with sub-standard or limited access to care and medications (over 200,000 PLWH who need anti-retroviral medication do not have it), current federal-state partnership for financing care is not responsive to the fact that HIV is a national issue (e.g. New York State's generous Medicaid and ADAP programs provide everyone with HAART, while many states do not). Title I has not significantly shifted to primary care since HAART was introduced (e.g. there are states with ADAP waiting lists where Title I pays for transportation services).

The principal recommendation of the IOM report is the creation of a state-administered, fully federally funded national entitlement program for PLWHA that would establish a uniform benefit package that meets standards for HIV/AIDS care. Eligibility would be for all PLWHA with income under 250% of federal poverty level and would cost about $5.6 billion over 5 years. An estimated 50,000 more people would receive HAART, making it cost effective in terms of years of life extended. With this new program, ADAP would not be needed and Title I would be used mostly for people not eligible (e.g. undocumented immigrants) and as a way to get people into the comprehensive care program. The report recommends that the program have the same drug pricing as the Veterans Administration (the lowest level), which drug companies oppose. As an entitlement, it would not require reauthorization.

Mr. Cordero (in response to a question from Mr. Pressley): The CAEAR Coalition Policy Committee had a conference call to address the report. They want someone from the IOM committee to give a presentation to CAEAR to get a good understanding of it. The report was delayed, and so CAEAR and AIDS Action Council have delayed putting out their policy positions until this report came out. The reauthorization sub-committee is analyzing it. Some recommendations in the IOM report are consistent with CAEAR positions (e.g., drug pricing). Other items are more controversial, like local control. The core recommendation of creating a new entitlement program is not likely to pass in the current political and fiscal environment. There are two general camps of opinion: one supports most elements like centers of excellence; the other, which is reflected in a press release from the US Department of Health and Human Services, is that the recommendation is dead on arrival.

Mr. Pressley: Maybe Congress can pick out pieces of the report that can be implemented. Many in the community were afraid that the CARE Act would be turned into block grants.

Mr. Cordero: Block granting was one of 7 possible options the IOM did not go with. CAEAR is integrating this into its policy paper, as well as opposition to potential amendments it opposes, like combining Titles I and II or block grants.

Mr. Barnes (*in response to a question from Mr. Petro*): Title I would lose everything but some support services and the Medicaid share would be lifted. The proposal would benefit New York, as it would free up much local money. There is one other disease-specific entitlement (end-stage kidney disease for dialysis) through the Medicaid system, but it is not means tested. There was also discussion in the IOM committee that this is basically national health insurance for one disease, but Congress has already created a disease-specific program with the CARE Act.

Dr. Abramowitz: This is a radical proposal. The fundamental issue is that many states have not invested like New York and do not want to tax their residents to provide services. Does this mean that we will have to do this for education, etc?

Mr. Halperin: The report is provocative. Title I has never done a good job of demonstrating the effectiveness of its services (e.g., outcomes). It is unfortunate that we do not have this data.

Mr. Barnes: The IOM Committee was trying to answer a question. We knew it was meant to be provocative, e.g. about no unduplicated client count 15 years and billions of dollars later, and that some locations do not have equity. This is also a warning to the AIDS community that the system is not working optimally for PLWHA and that if they do not address it, it will be addressed for them (e.g. by HHS staff).

Dr. Abramowitz: We can not run programs and limit investment in infrastructure. We cannot show effectiveness without client level data, which the administrative cap prevents us from obtaining.

Mr. Cordero: Thank you to Mr. Barnes for giving us these insights on the IOM report. We will continue this discussion at the Planning Council and community levels.

Agenda Item #6: Committee and Workgroup Reports

Mr. Klotz: The Finance Committee met yesterday. MHRA presented the FY 2003 close-out report. At the end of FY 2003, the EMA had spent 97% of its total grant award. This is possibly a record level of spending, and DOHMH/MHRA should be commended for working so diligently to ensure such a high spending rate. This guarantees that we will get the maximum points on our application for spending. About one third of the under-spending is in one category – Ambulatory Outpatient Care, and the Committee has asked MHRA to report back on why this is the case.

The Committee also discussed the implementation of the reprogramming plan to ensure maximum spending in this fiscal year. If there is an enhancement to a category, the grantee will not enhance programs that are under-spending, only those that are spending fully. Thus, if not all of the funds allocated in the reprogramming plan can be allocated to a category, the funding automatically falls to the next ranked priority on the list. The Finance Committee supports this and feels that this should be explicitly authorized by the Council, similar to the authorization to move funds within the large category groupings ("the bubbles"). Mr. Hemraj will present a motion to this effect at the next full Planning Council meeting.

The Committee will also recommend to the By-laws task force that they formalize which committee in the new structure will oversee the allocation of funds for Planning Council support. This has been done in an ad-hoc fashion by the EC, but the Finance Committee feels that a specific committee should be charged with this task. Finally, the survey of the administrative mechanism will go out this week. The results will be reviewed at the August Finance Committee meeting and will be presented to the EC the next day for approval for the application.

Mr. Pressley: The P&E is reviewing the workgroups' reassessed templates, with Mental Health and Infrastructure completed to date. There may be a need to have some way to make sure that all reassessed templates have the data to know if they are promoting access to and maintenance in primary care.

Ms. Curry: The Infrastructure Workgroup finished its reassessment and did not meet this month.

Rev. Troia: The Social Services Workgroup has completed reassessing food and nutrition services, case management, legal services, supportive counseling, and custody planning (which was integrated into supportive counseling). We expect to finish buddy services and transportation next week. I will recuse myself from discussions of the transportation template for conflict of interest reasons. Thank you to Mr. Klotz and Ms. Gonzalez, who have been great shepherding this process.

Mr. Halperin: I have not been to the Social Services Workgroup meetings, but from what I hear, they are doing great work. That kind of work should not be lost in the restructuring.

Mr. Ng: The Housing Workgroup finished reviewing its last template and switched to HOPWA issues, writing to the City Council on the budget.

Dr. Abramowitz: The Data Committee spent a lot of time discussing its role, particularly in relation to the P&E and how research initiatives are approved. This discussion may be moot with the new structure.

Mr. Halperin: What was sad about those discussion is that so many smart people on the Data Committee felt under-appreciated, which alienates them from the system.

Agenda Item #7: New Business

Mr. Cordero: The Titles I and III coordination meeting will be held on June 30, led by Ms. Nagy. Please welcome new OPAC staff member Beth Cohen-Barusek, who will be working on the P&E team as a Program Coordinator for Research and Evaluation. She helped found the DOHMH HIV Library, which is now the general DOHMH library. With Ms. Cohen-Barusek, we will have additional capacity for literature searches and in-house research.

Mr. Cobb: The R&M thanks Mr. Dwyer for his hard work. The application process for new Planning Council members is proceeding, with 21 applications received to date. The focus is on recruiting Latino males. Half of the applicants so far are consumers and 1/3 are Latino males.

Ms. Nagy: We have been promoting the application heavily.

Mr. Cobb: I went to 3 of 5 community forums where I heard the theme that access to the Planning Council is limited. Our Planning Council has a high number of governmental representatives. We want to make sure that we are in compliance with HRSA requirements. Perhaps some governmental representatives can consider giving up their seats.

Ms. Nagy: This issue should he brought to the By-laws Task Force.

Mr. Halperin: Twenty-one applications is not enough. We need more non-aligned consumers. Targeted outreach should be done, as well as an ongoing development process for people who are appointed.

Mr. Cordero: We still have until June 11. Last year we got a large number of applications in the last two days before the deadline.

Ms. Curry: I agree with Mr. Halperin that we need ongoing training and support. It was difficult for me as a new member.

There being no further business, the meeting was adjourned.

Minutes approved by the Executive Committee on July 8, 2004

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Robert Cordero
Acting Governmental Co-chair