



Meeting of the

## HIV Health and Human Services Planning Council of New York

February 17, 2005

3:00 – 5:00 PM

Queens Borough Hall

### MINUTES

**Members Attending:** B. Stackhouse, PhD (Acting Governmental Co-chair), P. McGovern (Community Co-chair), S. Hemraj (Finance Officer), R. Abadia, B. Agins, MD (for H. Cruz), P. Avitabile (for E. del Campo), M. Bacon, R. Bonilla, K. Butler, E. Camhi, F. Carroll, P. Catapano (for S. Abramowitz, PhD), E. Cates, R. Chavez, L. Dolloway, I. Feldman, L. Fraser, I. Gamble-Cobb, R. Gonzalez, M. L. Hernandez, J. Hilger, J. Katz (for C. Barometre), J. Lopez, H. Mateo, D. Ng, A. Palermo, T. Petro, J. Pressley, A. Richardson, E. Telzak, MD, T. Troia

Members Absent: K. Ashley, MD, M. Barnes, G. Brown, MD, C. Cobb, C. Craig, B. Curry, C. Dzubilo, J. Grimaldi, MD, H. Hernandez, W. Okoroanyanwu, MD, T. Osubu, A. Paige-Bowman, J. Pedraza, A. Raiola, E. Santiago, D. Woodard

**Staff Present:** OAPC: G. Moon, D. Klotz, S. Bailous, I. Gonzalez, C. Silva, R. Molina; DOHMH: J. Park, S. Forlenza, MD, MPH, Moupali Das-Douglas, MD, F. Machlica; MHRA: R. Miller, P. Jensen

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#### **Agenda Item #1: Welcome/Introductions/New HIV Case/Minutes**

*Dr. Stackhouse:* Welcome to the first Planning Council meeting in Queens. We apologize about the miscommunication regarding the award. Other EMAs were also confused by a communication from HRSA.

*Mr. McGovern* reviewed the rules of respectful engagement.

*Mr. Hemraj* introduced the moment of silence.

*Dr. Das-Douglas:* As most of you know from the press, a strain of rapidly progressive, dual-tropic HIV that is resistant to three classes of anti-retroviral drugs has been diagnosed in NYC for the first time. The patient, a man who has sex with only men and is a crystal meth and other drug user with multiple partners, has had rapid immuno-depletion. Only Fuzeon, the sole drug in the new class of fusion inhibitors, is active against this virus, but mono-therapy is not effective against HIV. People who are on treatment for prolonged periods can develop multiple mutations that resist their drug regimen and drug resistance is common in people on long term HIV therapy, but it is unusual in primary infection. In addition, his virus can use two types of receptors to enter CD4 cells. This combination of drug resistance and rapid progression to AIDS has not previously been diagnosed in NYC

DOHMH is recommending that doctors now do resistance testing for all newly diagnosed HIV infections. Doctors also need to watch out for seroconversion syndrome, which resembles the flu. Other steps to

prevent 3DCR in people on HAART are: 1) Improve patient adherence to anti-retroviral treatment to prevent development of drug resistance; 2) At every visit, provide prevention counseling to HIV+ patients; 3) Emphasize safer sex, condom use, clean needles and works; 4) Emphasize how important it is NOT to combine crystal meth use with antiretroviral therapy or sex; 5) Emphasize that people who are already positive can be infected with a new strain, and that this could complicate their treatment and worsen their prognosis.

DOHMH is attempting to detect 3DCR HIV in newly infected patients. This means: 1) Test for drug resistance in all persons with newly diagnosed HIV; 2) Obtain partner names and contact information from HIV-positive persons and provide or refer for HIV testing; 3) Increase prevention activities, esp. for high-risk groups. Also, doctors have to discuss risk reduction with their patients.

Even though there has only been one case of this highly resistant and rapidly progressive strain, we don't know how many other people have this strain. Most people newly diagnosed with HIV will have a strain that is susceptible to drugs. This strain is not a reason to avoid testing because drugs cannot help you. Most strains are still susceptible to drugs. DOHMH decided to go public with this because it is irresponsible not to inform the community and medical providers about this case and the implications for MSM, crystal meth and other party drug users as well as the general community. DOHMH also needs to develop surveillance systems to better comprehend the epidemiology of drug resistant HIV.

Finally, this is a wake up call to the MSM and other communities need to reduce risk behaviors. Get tested. If you're positive, get care and be safe. If you're negative, stay safe.

*Dr. Das-Douglas (in response to a question from Mr. Butler):* This case was probably transmitted from a person who was treatment experienced, since it is resistant to all 3 classes of drugs.

*Dr. Das-Douglas (in response to a question from Mr. Lopez):* T-20 (Fuzeon) trials were done in people who had failed other regimens, and it was approved as salvage therapy. It is a difficult to take drug requiring multiple daily injections, and we need to reduce the burden of medication to improve adherence. Its use will become more prevalent as people fail other regimens, and we need to encourage drug companies to keep new meds coming. DOHMH is providing extensive support to hospitals and other providers. I know that doctors do poor job talking about prevention. We are also working with CBOs to increase referrals. We are starting a public health detailing program, sending public health workers to doctors' offices to talk about HIV and how to talk to patients.

*Dr. Das-Douglas (in response to a question from Ms. Hernandez):* This strain can also be a problem for heterosexuals. Some MSM also have sex with women, and DOHMH will support prevention to all communities, but since this problem is starting in the gay community, we need to target high risk takers immediately. In this case, it is a resistant strain of HIV-1, but resistance can develop in other strains.

The minutes of the January 20, 2005 meeting were approved, with one typo corrected.

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

*C. Chang:* Community-based treatment education, such as that provided by ACRIA, provides information that doctors and nurses do not have time to give, and peers educators can give a personal perspective. Many people enter into care through our education efforts. The recently released Title I RFP would mean that only people already in care would have this service. Also, the African Services Committee supports this, as their clients have benefited greatly from this service.

*L. Peña:* The Air Bridge program provides continuity of care. Clients rely on it for medical care, social services and housing.

*E. Nieves:* When I first came to New York from Puerto Rico, I was in terrible shape. The service system in PR could not handle my situation. Air Bridge connected me with medical care, financial help and social services.

*M. S. McLaughlin:* Special Needs Plans are starting soon. There will be forums on this for consumers and providers in Brooklyn and Queens.

*E. Rivera:* Air Bridge connected me with medical care when I came from Puerto Rico and offered me a lot of support.

### **Agenda Item #3: PLWHA Advisory Group Report**

*Ms. Carroll:* At the last PLWHA Advisory Group (AG) meeting, Mr. McGovern attended. We also had a presentation on the 2005-8 Comprehensive Strategic Plan. There will be a memorial for Cliff Moseley. We urge all clients at Title I agencies to complete the CAB survey by March 11<sup>th</sup>. Finally, we hope that the Queens consumers here will get more involved in the planning process.

*Ms. Hernandez:* We need community forums in Spanish for people who only speak Spanish. They have special needs for services. I move that we have a forum in Spanish.

*Ms. Moon:* Community forums are intended to give people an opportunity to provide input to the Council on service needs. We accommodate everyone and we can provide translation services.

*Ms. Hilger:* Perhaps we can hire a translator to make them more inclusive.

*Mr. Abadia:* Even if we have only one forum in Spanish for the whole City, that would be a good first step. The AG did focus group only in Spanish and found big differences in care for monolingual Spanish-speakers. We should always offer translation at all meetings.

*Mr. Camhi:* There is a similar issue with other non-English speaking communities. Perhaps we can communicate in multiple languages to the community that we accept public comments in many ways, not just through forums.

*Ms. Mateo:* It would be good if we made it easier to become part of planning process, e.g. providing a translator.

*Mr. Abadia:* To clarify, Ms. Hernandez said that ideally there should be Spanish forums in all boroughs, but one citywide forum would be a good step. This shows the problem with translation. Also, HRSA's charge is to reach underserved communities, and monolingual Spanish-speakers have lower rates of accessing care.

*Dr. Stackhouse:* In the past, we have had the flyer in both languages, with a call for written testimony. We will do that in the future.

*Ms. Moon:* We offer translation services, but need to know in advance to arrange to contract for it.

*Dr. Agins:* The State AIDS Institute would be interested in co-sponsoring a Spanish forum.

*Mr. Lopez:* It should be written on the Council calendar that one can arrange for translation services.

The motion was restated: to hold at least one City-wide community forum in Spanish. **The motion carried unanimously.**

## Agenda Item #4: FY 2005 Spending Scenario

*Mr. Pressley:* I want to preface this discussion by saying that Ms. Mateo and I chaired a very difficult process. We think we did the Priority Setting & Resource Allocation Committee (PSRA) best the job possible. To provide some context, in FY 2004, the New York EMA's award was \$122,103,117, the largest award in Title I history. At the same time 41 of the 51 EMAs received funding cuts. This year, we are expecting a cut. Many EMAs advocated for themselves in Washington.

*Ms. Mateo:* PSRA met to develop a plan ahead of the award announcement to address a potential cut in the EMA's funding, and to evaluate the spending plan and develop potential cuts. We developed the following scenario planning principles with the goal of maintaining a continuum of care that serves as many communities as possible: 1) Maintain Title I funded services that provide access to and maintenance in quality HIV/AIDS primary care; 2) Ensure that Ryan White Title I funds are the payer of last resort; 3) Utilize the best available accurate and detailed information.

We based any scenario planning on last year's comprehensive review of all Title I services. PSRA did not re-rank the priorities as set by the Council at the end of last year's planning cycle. PSRA reviewed the resource allocation of the spending plan and determined how resources should best be used. The possible scenarios we discussed were: 1) Across the Board (ATB) Cuts; 2) Proportionate Cuts; 3) Tier I Hold Harmless. We also voted to recommend the formation of an ad hoc task force of PSRA to develop a process for determining what services are essential and/or no longer needed and to evaluate data issues/needs.

*Mr. Pressley:* The task force will meet regardless of the award, as we need a plan that reflects actual need. We intend to have them complete their work in time to inform the next priority setting process. If we do not make the hard decisions, the federal government might do that for us.

*Ms. Mateo:* The final recommendation for the spending plan, which was accepted by the Executive Committee is: an ATB cut up to 15%, with the exception of the following four programs, which will be held harmless beyond a 5% cut: 1) Planning and Evaluation initiatives; 2) Quality Management; 3) Data Link; 4) Planning Council support.

*Mr. Pressley (in response to a question from Mr. Chavez):* The task force's work will require coordination with the Access to Care and Maintenance in Care Committees.

*Mr. McGovern:* The task force was created out of frustration that we did not have specific data to evaluate services. They will help determine what kind of data we need to see which programs have evolved and are still essential or not. We need more than anecdotal information. ATC and MIC have a different charge – to work with the Integration of Care Committee's framework and look at what kind of services fill those out, rather than where do existing categories fit.

*Mr. McGovern (in response to a question from Mr. Lopez):* We will clarify the work plan and time line.

*Mr. Butler:* It is important to involve the Consumers Committee in this process.

*Mr. Abadia:* The Consumer Committee will also be looking at every category and working with the task force. Unlike the AG, the Consumers Committee is open to the public, not just PLWHA.

*Mr. Camhi:* We need to have a standard for both cuts and increases. Making selective increases contradicts the idea of making ATB cuts.

*Mr. McGovern:* I agree. We are doing ATB cuts now only because we do not have enough data, but we want to have data for the future for planning for all scenarios.

*Mr. Petro:* ATC an MIC will still look at individual categories. The task force is meant to determine the factors that will help in ranking and dollar allocations. We need a rational way to assess what services are more important than others. PSRA would take product and decide what to do with it (e.g., a tier system).

*Mr. Pressley:* I agree. I want to make sure that it is understood that the task force's work will lay a foundation by the end of the year for a new paradigm for planning.

*Mr. Hemraj:* It is clear that with the change in the epidemic we have to look at the whole service portfolio to make sure it reflects needs, is truly payor of last resort, and is ranked appropriately.

*Mr. Pressley:* The recommendation in the presentation is a motion endorsed by the EC.

*Mr. Hilger:* Mr. Petro's description of the task force's role is the more accurate than the description in slides.

*Mr. Pressley:* Correct.

*Mr. Petro:* How many treatment education programs will be terminated and when, and what was the rationale for discontinuing them?

*Dr. Stackhouse:* We will save discussion of this for the grantee report.

**The motion carried 27-0-4 (Y-N-A).**

*Dr. Stackhouse:* Thanks to PSRA for their hard work.

### **Agenda Item #5: Finance Committee Report**

*Mr. Hemraj:* The Finance Committee met this month to review the FY 2004 third quarter spending report. The EMA is doing well and is in line with last year's record spending (and much better than the previous two years). Spending for MAI in particular is the best ever. Spending is keeping pace in spite of the record \$18M increase in the overall Title I award. In base funding, there is higher than average under-spending in two categories: Capacity Building and Housing Enhancements for Special Populations, due to late starting contracts and a reporting lag, respectively. \$4.6M was uncommitted but will soon be totally committed through implementation of the Planning Council's reprogramming plan (most to the ADAP pools, some to Food and Nutrition programs, as per the plan).

*Mr. McGovern:* I want to congratulate the grantee on expediting the contracting process.

*Rev. Troia:* Regarding a motion made at the EC meeting on funding for Supportive Counseling and Legal Services, it was agreed that was an error in calculating the amount after elimination of Custody Planning. The amount in the current spending plan reflects about \$621,000 moved from Supportive Counseling to Legal Services. Thanks to the grantee staff and to Tracy Welsh and Cynthia Knox for identifying the problem.

### **Agenda Item #6: Grantee Report**

*Ms. Hilger:* I apologize for the confusion regarding the award announcement. We had heard that Atlanta got their award. We then saw an e-mail from HRSA with the title "Notice of Grant Award", which had a form attached that is always used for grant award announcements. We did not realize that it was a notice of FY 2004's award with all conditions of award met. We told HRSA to be more explicit in the future what the intention of their e-mail is, especially since everyone is on pins and needles waiting for the FY 2005 award announcement.

The RFP proposal review is under way. After the award is announced we will be able to announce which providers will get funding. Contract take-downs have been completed, including for State-administered contracts, resulting in a final take-down amount of \$879,000. Finally, MHRA is working on the contract renewal process, which is on track.

*Mr. Park (in response to a question from Mr. Lopez):* New York's HOPWA award was cut by 17% this year (\$9.7M), the largest cut in the country. We are responding to HUD about this. The HOPWA grant is all formula, not competitive like Title I. The federal government is not putting funds into HOPWA, and new cities have been added to the program. We are trying to figure out how to absorb the cut and will be meeting with our community partners. We are encouraging housing providers to advocate in Washington.

*Mr. Lopez:* I suggest absorbing the cut from the HOPWA "swap".

*Ms. Hilger:* Responding to Mr. Petro's question earlier, the Health Workgroup made the recommendation, which the Council approved, to combine treatment education and treatment adherence. They felt that Adherence programs would include treatment education funds and would contain a treatment education component. The category is being re-bid. Current contracts run through August 31st, then new contracts begin.

*Dr. Stackhouse:* It's good to see Ms. Hilger back at the Council and doing well.

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

*M. Gold:* The number of seniors with HIV is increasing. Seniors need prevention and care services.

*R. Jones:* We need more forums to hear from PLWHA, especially when considering cuts. We also need to let consumers know about grievance procedures.

*M. Jory:* Thank you for restoring funding for Legal Services.

*B. Moon:* The HIV Law Project helped me with benefits and to advocate for myself.

*F. Grant:* The Council needs to represent the community.

*G. Gorsky:* The HIV Law Project helped me advocate for myself.

*M. Cera:* Legal services empowered me. Now I know I have rights.

*A. Preston:* Thank you for restoring most of the funding for Legal Services. The public comments show how necessary this program is.

*J. Rivera:* If you need to make cuts, look at poor performing programs, which requires additional funds for evaluating programs.

*Rev. Troia:* Please don't have Data Day 2 on Good Friday.

*Mr. Abadia:* Make sure to complete the AG's CAB survey.

There being no further business, the meeting was adjourned.

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

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Bill Stackhouse, PhD, Acting Governmental Co-chair