



Meeting of the
PRIORITY SETTING AND RESOURCE ALLOCATION COMMITTEE
Marya Gilborn and Charles Shorter, Co-Chairs

June 25, 2009
The Ryan Center
9:30 am – 12:30 pm

Members Present: Sean Cahill, PhD, Felicia Carroll, Eunice Casey (alt. for Terry Hamilton), Sharen Duke, Soraya Elcock, Terri Faulkner, Linda Fraser, Marya Gilborn, Fabienne Laraque, MD, MPH, Matthew Lesieur, Sharon Mannheimer, MD, Hilda Mateo, Jan Carl Park, Dena Rakower, Charles Shorter, Derrick Weekes (alt. for Jennifer Irwin)

Members Absent: Joan Edwards, Antionettea Etienne, Steve Hemraj, Peter Laqueur, Reynolds Mulero, Tom Petro

NYC DOHMH Staff Present: Nina Rothschild, DrPH, Anthony Santella, DrPH, Jessica Wahlstrom, Darryl Wong

Public Health Solutions Staff Present: Lauren Feldman Hay, Stefani Janicki, Gucci Kaloo, Rachel Miller, Grace Shin

Others Present: Victor Benadava, Alexandra Duncan, Mallory Marcus, Pedro Mateu-Gelabert, PhD

Material Distributed:

- Agenda
- Minutes from the June 4th Meeting
- 2009 Consumer Focus Groups Preliminary Report
- NYC Ryan White Part A Service Category Scorecards 2006-2008
- Payer of Last Resort Tool Update
- Planning Council FY 2009 Priority Setting Tool

Introductions/Moment of Silence/Review of the Meeting Packet: PSRA Committee members introduced themselves. Victor Benadava led the moment of silence. Jan Carl Park reviewed the contents of the meeting packet

and noted that one of the major assignments for this meeting is to finish reviewing the scorecards and other data so that we can take the priority setting tool when we meet again in July and either reaffirm the rankings, consider repopulating the tool, or simply make adjustments to the tool.

Review of the Minutes: Committee members reviewed the minutes from the previous meeting on June 4th and requested two changes. The amended minutes were accepted by all present with no votes in opposition and four abstentions. Committee members agreed to review the minutes from the May 28th meeting at the next PSRA gathering on July 7th.

Consumer Focus Groups: Alexandra Duncan and Pedro Mateu-Gelabert, PhD, consultants with the Department of Health and Mental Hygiene, made a joint presentation on the consumer focus groups. A copy of the presentation is available on the Planning Council website at www.nyhiv.org. A total of 125 consumers participated in focus groups and completed a brief survey concerning Ryan White services. Several points were made concerning the characteristics of the groups, the findings, and the strengths of qualitative vs. quantitative data:

- A total of 12 focus groups were held in all five boroughs.
- Some focus groups focused on specific demographics: one focus group, for example, consisted of transgender individuals (in response to Planning Council members' interest in this group), another included only youth and young adult members, and another was comprised of recent releasees from jail/prison.
- The demographics of participants were similar to the demographics of the 2008 consumer focus groups: 55% of clients were male, approximately 50% identified as African American or Black, and all five boroughs were represented.
- Coming to terms with an HIV-positive diagnosis and taking ownership of HIV status can take years.
- Consumers want to be addressed as whole persons: for example, a transgender individual who is homeless wants his or her doctor to understand the difficulties entailed in adhering to a medication regimen when constantly moving from place to place.
- Consumers mentioned the perverse incentives to poor health: HIV-positive individuals generally must have a low CD4 counts in order to obtain services and, therefore, sometimes neglect to take care of themselves in order to compromise their well-being and obtain care.
- Consumers draw information not just from social and medical service providers but also from peers and support group participants.
- Instability in insurance coverage creates stress and deters consumers from accessing/remaining in care. Consumers fear losing coverage

through a change in employment, non-renewal of Medicaid, and changes in coverage within medical plans.

- Consumers are generally very happy with ADAP (the AIDS Drug Assistance Program). Pharmacists are also helpful when they remind consumers about refills.
- Some consumers are very happy with case management services, while others are deeply unhappy and feel that case managers withhold information and services.
- Housing is essential for accessing and remaining in care.
- Substance abuse services are very helpful for facilitating access to and maintenance in care.
- Consumers help themselves through advocacy.
- Consumers don't necessarily want to be seen obtaining services in their own neighborhood and would rather travel elsewhere for more privacy.
- Different service sites have varying enforcement of eligibility criteria.
- Manhattan has the best services.
- Care on Staten Island is unacceptable. Problems include stigma, the absence of a DAC (Designated AIDS Center), limited time with providers, and few prevention services.
- Transgender participants describe barriers due to stigma, provider bias, inability to change documents to reflect correct gender identity, and concern about interactions between hormone therapy and HIV medications. Concerns about interactions may interfere with antiretroviral adherence.
- Consumers over the age of 50 feel that providers are uncomfortable discussing sexuality with them.
- Huge gaps in knowledge exist between CAB (Community Advisory Board) members and non-members. Some CABs are good, and members feel that their voices are heard, while others involve fighting and arguing and include few meaningful discussions.
- The majority of the participants have experience with the system and have learned how to navigate it.
- The qualitative data generated in focus groups provides layers of richness not necessarily available through survey research. Data from consumer groups cannot be generalized, however, and can be skewed by group dynamics.
- The quantitative data provides information on demographics and on satisfaction with services as well as on participants' assessment of how important particular services are for accessing and remaining in care.
- Participants were asked about service categories as defined by HRSA, not as defined by the New York EMA; therefore, they provided information on the importance of dental services (funded by HRSA), even though the HIV Health and Human Services Planning Council of New York de-funded dental services in New York City.

Recommendations from the focus groups include:

- Help consumers to become their own advocates;
- Clarify eligibility criteria for services;
- Explore ways to reward proactive care and positive behaviors;
- Make information about HIV services widely available;
- Aid consumers in navigating health coverage plans;
- Help consumers to access quality housing;
- Facilitate a one-stop shopping model of care (recognizing that some consumers don't want to be seen at an agency providing exclusively HIV services);
- Increase consumer awareness of CABs and the responsiveness of agencies to reasonable recommendations from CAB members.

Matthew Lesieur asked Dr. Mateu-Gelabert whether he can break down participant responses about case management: for example, are consumers more satisfied with non-HASA case management than with HASA case management? Dr. Mateu-Gelabert responded that HASA workers were perceived as rude and dismissive. HASA services were also described as cookie-cutter, rather than tailored to individual client needs, and acceptable for people who basically have their lives together but not for all PLWHAs. Medical case management services were more satisfactory than HASA case management services. Felicia Carroll asked whether anyone who was unhappy with case management discussed changing case managers. Some consumers, indeed, felt frustrated if they perceived that they were just a number in a caseload; they didn't like being viewed as a commodity. Ms. Carroll also asked whether participants discussed access to nutritional services and food, but this topic didn't come up very frequently during focus groups.

Marya Gilborn reminded Committee members that they are specifically interested in finding out about services that help with accessing and remaining in care. Ms. Gilborn also noted that the presentation on the focus groups comes with a caveat that focus group members cannot be viewed as representative of the entire population of consumers and asked whether we should really be using the data to make decisions, given this limitation. Dr. Mateu-Gelabert responded that qualitative research has texture and validity and may not be the opinion of 100% of consumers but is nevertheless good quality data. Dr. Fabienne Laraque noted that DOHMH doubled the number of participants in focus groups this year and recruited from a larger pool. DOHMH also supports the CHAIN cohort study of PLWHA, and members of that larger group of research subjects are more representative of people receiving services. Sharen Duke requested a list of agencies from which focus group participants were recruited.

Ryan White Service Category Scorecards: Dr. Santella led the discussion of the service category scorecards, noting that data is not presented in as much detail for programs that are ending.

Dena Rakower underscored the importance of knowing whether a few contracts over- or under-performed and might influence the performance of a particular service category.

Committee members discussed the monitoring of components of care. Dr. Laraque stated that in a new model of care such as medical case management, the performance of programs but not the performance of different units that have been subsumed into new programs would be monitored. We want to know, for example, whether PLWHA are in care consistently and whether their CD4 counts are increasing and their viral load is dropping when they are enrolled in the new medical case management model. Assessment of program performance should be based on outcomes, not on the monitoring of individual components of programs. Jan Carl Park asked about the Planning Council's role in overseeing the performance of programs, but Ms. Gilborn replied that this is another conversation. Ms. Rakower advocated for following whether individual components of larger programs (i.e., treatment adherence as a component of medical case management) are working. Ms. Gilborn asked what tools the PSRA Committee would have to understand what's going on within service categories.

Committee members discussed the information provided on the scorecards for various service categories.

Outpatient Medical Care (OMC):

- These contracts will end on November 30, 2009.
- In FY 2008, 32 contracts served more than 8,000 clients.
- This service category includes ADAP/ADAP+ and includes 6 sub-contracts between New York State and Public Health Solutions.

Outstationed Medical Care Teams in SROs (OMS):

- The two contracts in this service category will end on November 30, 2009.
- Clients in SROs are predominately living with AIDS, not just HIV-infected.

Primary Care Development (PCD):

- These contracts are ending on November 30, 2009.

Rikers Island Transitional Services Project (PRS):

- Several CBOs work closely with DOHMH on the Rikers Transitional Services.

Supportive Counseling and Family Stabilization Services (SCF):

- The number of family members served through this service category (180 in FY 2008) is higher here than for many other categories.

Tuberculosis Services (TBS):

- TB services are ending at the end of November and will be reported as part of outpatient medical care.

Transportation Services (TRN):

- One contract served a total of 149 clients in FY 2008.

MAI Overall:

- The MAI data is reported separately from Base data because MAI runs on a different funding cycle. The spending data for MAI in FY 2008 will be complete in October of 2009. The data on the HIV status of many of these clients, therefore, is unknown/pending.

Treatment Adherence:

- This service category enrolls more clients who are age 50+ than many other service categories.
- When discussing this service category, Committee members recommended that the portion of the service category scorecards which describes the clients' HIV status should be changed to read as either HIV-positive (non-AIDS) or CDC-defined AIDS.
- Committee members noted that for this category, the balance between HIV+ and CDC-defined AIDS is almost 50/50.

Drop-In Center for HIV+ Prison Releasees (TSC):

- This service category will be re-ranked according to its Base equivalent.

Committee members agreed on several changes for the next iteration of the scorecards:

- Page numbers will be added
- Base rankings will be assigned to MAI service categories
- Clients will be identified as HIV-positive (non-AIDS) and CDC-defined AIDS
- A note will be added to explain that the number provided for drawdown issues refers to the number of agencies, not to the number of issues.

Dr. Laraque noted that the only way to avoid duplication in provision of services is to give each client a swipe card to ensure that he or she does not receive the same benefit from multiple agencies.

Payer of Last Resort: Jessica Wahlstrom of the Policy, Planning, and Implementation Unit gave a presentation on the payer of last resort tool. A copy of her presentation is available on the Planning Council website at nyhiv.org. Originally created by the New York Academy of Medicine under contract with the NYC DOHMH to provide the Planning Council with information about payers for services used by PLWHA, the tool has been revised and updated to include new information on capacity and eligibility. Ms. Rakower noted that the revised tool doesn't provide information for PLWHA who have private insurance but also have gaps in their coverage. Dr. Santella responded that a complete version of the tool would include information on private funding, but this version – with information on public funding – is sufficient for Planning Council purposes. Staff from the Care, Treatment, and Housing Program will update the tool on a yearly basis. Dr. Santella urged Committee members to notify staff from the Policy, Planning, and Implementation Unit or the Planning Council Unit if they have concrete information about changes and updates.

Agenda for Next Meetings: Jan Carl Park promised to walk PSRA Committee members through the payer of last resort tool at the next PSRA Committee meeting on July 7th. Committee members will examine how service categories were ranked last year and whether we need to adjust them this year. At the subsequent meeting on July 16th, Committee members can use the scorecards and other instruments to allocate resources. The final result of this effort will be the spending plan for FY 2010. Committee members inquired about the role of CHAIN (the longitudinal cohort study of PLWHA in New York City and Tri-County conducted by researchers at Columbia University with input from Care, Treatment, and Housing Program staff and from Public Health Solutions) in providing information on consumer priorities,

but Dr. Laraque stated that the CHAIN researchers are not really gathering new data and that a CHAIN update is not necessary.

At the PSRA meeting on July 7th, DOHMH staff will also provide PSRA Committee members with information about the three new program guidances on Food and Nutrition Services, Outreach Services for Homeless and/or Street Youth, and Transitional Care Coordination Services for Homeless or Unstably-Housed People Living with HIV/AIDS developed by the Planning Council's Integration of Care Committee.

Rachel Miller of Public Health Solutions raised a question about the planning process. She thought that the Planning Council had committed previously to a three-year cycle and would not necessarily be re-prioritizing and re-allocating resources on an annual basis. Dr. Laraque responded that PSRA Committee members should not think that they must re-rank service categories and make changes on an annual basis but, rather, that they may readjust and reexamine and reallocate. Mr. Park noted that PSRA Committee members have new information from the scorecards and the consumer focus groups but don't necessarily have to re-evaluate every service category in the PSRA tool.

Ms. Miller also reminded Committee members that they will need to reaffirm the reprogramming plan at the next meeting.

Linda Fraser commented that the Division of Mental Hygiene is anticipating some losses in Medicaid funding and noted the importance of not reducing the funding allocated to mental health services or lowering the mental health service category ranking.

Adjournment: The meeting was adjourned. Committee members will meet again on July 7th from 2:00-5:00 at The Family Center at 315 West 36th Street on the fourth floor and on July 16th from 9:30-12:30 at Ryan Chelsea Clinton at 645 Tenth Avenue (between 45th and 46th Streets) in the 2nd floor conference room.