Meeting Minutes
NEEDS ASSESSMENT COMMITTEE
Lee Hildebrand, DSW and Mimi Pinon, NP, Co-Chairs

July 7, 2011
Federation of Protestant Welfare Agencies
281 Park Avenue South
10:00 am – 12:00 pm

Members Present: Angela Aidala, PhD, Randall Bruce, Martin Bruner, Guillermo Garcia-Goldwyn, Lee Hildebrand, DSW, Sabina Hirshfield, PhD (alt. for Mary Ann Chiasson, DrPH), Rosemary Lopez, Frank Machlica, Tamella McCowen, Freddy Molano, MD, Ariel Negron, Jr., Jan Carl Park, Mimi Pinon, NP, Marcy Thompson, Ricardo Vanegas-Plata, DDS

Members Absent: Terri Faulkner, Carlos Manuel Gonzalez, Jose Gonzalez, Jennifer Irwin, Rebecca Kim, Barbara Kobrin, Julie Lehane, PhD, Leslie Mack, Don McVinney, Glen Phillip, Kate Sapadin, PhD

NYC DOHMH Staff Present: Taiwanna Messam, Nina Rothschild, DrPH, Ellenie Tuazon

Public Health Solutions Staff Present: Derek Coursen, Wilson Joseph

Others Present: Felicia Carroll, Ashley Grosso, Mallory Marcus

Material Distributed:

- Agenda
- Minutes from the June 9, 2011 Meeting
- Return to Care Survey Presentation by Ellenie Tuazon
- Executive Summary of the 2009 Consumer Focus Groups Report
- List of CHAIN Report Topics
- Planning Council July 2011 Month-at-a-Glance
- Planning Council Calendar for July 2011

Welcome/Introductions/Moment of Silence/Review of the Minutes:
Committee Co-Chairs Lee Hildebrand and Mimi Pinon welcomed meeting

participants. Committee members introduced themselves and observed a moment of silence. The minutes from the June NA Committee meeting were accepted.

Return to Care Survey: Ellenie Tuazon of the Research and Evaluation Unit of the Bureau of HIV/AIDS Prevention and Control presented a study on HIV/AIDS patients who return to HIV primary care after 6-9 months out of care. Services most frequently used included primary care, HIV counseling, and treatment adherence. A service not received but needed was dental care. The goal of the study was to understand the range of factors behind the lapses and returns. In order to be included in the study, the individual had to have a gap of 6 months or more prior to return to care and 3 or more months of continuous enrollment in the program since return to care. Interviews were completed in-person face-to-face using ACASI.

Almost 100% of subjects said that they really needed primary medical care. Reasons for not receiving care included feeling hopeless or overwhelmed, having a good CD4 count and viral load, feeling good and not seeing any need to go to the doctor, forgetting or missing appointments, not wanting to think about being HIV-positive, not wanting to take HIV meds, not wanting to be seen at an agency providing HIV services, having unstable housing, and other reasons. Sixty percent of subjects said that feeling hopeless or overwhelmed was a very important reason why they stayed away from primary care. Twenty-three percent rated not being in stable housing as a somewhat to very important reason for not being in primary care. Other services accessed when out of care included emergency rooms and non-HIV medical care.

Why did these patients return to care? Only 56% received encouragement from their current primary care site. Thirty-four percent received encouragement from their non-primary care provider. Eighty percent said that they returned for another reason (e.g., their personal attitude or outlook changed, they received support from a family member, friend, or peer, or they became ill). Gaps in care were definitely influenced by depressive symptoms and health beliefs (e.g., feeling that there was no need for visits if the person wasn't sick or if the CD4 and viral load were good).

A limitation of the study was that it only focused on maintenance in care (MIC) providers, even though other service categories also have clients with return-to-care experience. Difficulties included trying to conduct a survey with people who are in and out of care. Recommendations include improving the integration of mental health assessments, mental health services, HIV health education, and social services; increasing collaboration with non-primary care service providers to identify and link out of care PLWHA to HIV primary

care; and increasing the partnership between providers of Ryan White Part A services to continue to improve client engagement in HIV primary care.

Rosemary Lopez expressed anger and frustration that Queens was not represented in the survey. Martin Bruner noted that mental health is at the core of why people fall out of care and that obtaining a mental health appointment can be difficult – in fact, the billing structure of various facilities almost makes providing mental health care not worthwhile. Dr. Hildebrand commented that seeing if there is a difference in retention rates between large hospitals and smaller CBOs would be interesting. Dr. Molano commented on the need to look at the 46% who forgot appointments. We need to look at clients outside of the hospital setting and work with hospitals to design corrective plans of action.

Dr. Hildebrand commented on the increasing emphasis now on linkage and navigation and the importance of seeing whether these initiatives make a difference. Martin Bruner noted that people may feel more comfortable in a small agency than in a big hospital. Mimi Pinon commented that we do a poor job of coordinating care as clinicians and administrators and noted the importance of one-stop shopping – primary care with linkage to HIV and mental health care.

Marcy Thompson noted the complications associated with tracking people in multiple data systems: the AIDS Institute uses AIRS, Ryan White is introducing e-Share, etc. Ms. Pinon recommended looking into regional health information sharing. Mr. Bruner pointed out the cost for workers to enter all the required data into the data systems and also the irony that clerical staff is often the first to be cut to save costs, even though this can create trouble for consumers.

Dr. Hildebrand noted that services have become increasingly medicalized and asked about the relationship between the medical and social service systems. Dr. Aidala pointed out the need for more education for patients about primary care and also to obtain at intake additional contact information such as a landline for another person who knows the patient in order to facilitate follow-up. She noted that she saw the same phenomenon in 1995 – namely, people thinking that they don't need care.

Mr. Park stated that people may feel overwhelmed and hopeless and that we need to give them self-management tools so that they can be empowered. Ms. Lopez stated that care coordination is not working and that referrals are staying insular within the medical community and not coming to CBOs. Jan Carl Park pointed out the value of community planning – namely, we can take what we hear during sessions such as this one and bring the information back to NYC DOHMH. Mr. Park also noted that not everyone needs the most

intensive form of care coordination – namely, not everyone needs to go to the doctor every three or six months. Dr. Ricardo Vanegas-Plata remarked on the small sample size in the return to care survey and asked whether we can really extrapolate based on this number of clients.

NYC DOHMH staff discussed a program under development for the newly diagnosed. The goal is to give the patients tools to manage their condition and take control of their illness. The program, known as Positive Life, will be provided by peers and is for PLWHAs across the City (not just those diagnosed in DOHMH facilities). One of the main points is to teach the patients about the importance of accessing and remaining in care.

Dr. Vanegas-Plata referred to a problem he had identified during a previous Needs Assessment Committee meeting – namely, that substance use services were being provided with Ryan White dollars to individuals who are not infected with HIV. Mr. Park informed him that those dollars would not be spent any more on uninfected individuals in the HRR category.

Ms. Tuazon promised Committee members to provide additional information on types of outreach at hospitals vs. at CBOs and also to check whether there are any agencies funded for this initiative in Queens.

Consumer Focus Groups: Needs Assessment Committee members briefly discussed the 2009 consumer focus groups. The "n" (i.e., the total number of participants in each group) is small, but the ideas expressed there are reflective of people's lives.

Formal Needs Assessment: Committee members discussed the way in which structural issues impact negatively on PWAs. Marcy Thompson noted that one of her clients is losing his Medicaid and will have to apply for ADAP via her agency but asked why Medicaid doesn't simply enroll him in ADAP. Ms. Pinon commented that the systems are obstructionist. Members agreed to discuss in the formal needs assessment the effects of interventions to address structural barriers such as medical homes, Medicaid managed care, and SNPs. Jan Park noted that DOHMH will have a consultant to look at the changing landscape – e.g., with health care reform

Mr. Park also noted that AIDS activists built the Ryan White program, consisting of a safety net of social services provided by community organizations. Maintaining this bedrock will be a challenge. He noted that ADAP programs are adjusting their eligibility levels down – namely, if someone has an income over a certain amount, he or she cannot be enrolled in ADAP – and nation-wide, more than 8,000 people are currently on ADAP waiting lists. How do we begin to put a cap on services in order to maximize the number of people receiving services? Mr. Park stated that the Integration

of Care Committee will decide whether or not to cap Ryan White services such as housing.

Public Comment: Ron Joyner noted that having HIV infection is not just about taking medications. We need to address mental health issues in order to give patients a sense of self-empowerment.

Thank You and Farewell: Mr. Park thanked Ms. Pinon, who is stepping down from the Planning Council, for her exemplary service as Co-Chair of the Needs Assessment Committee.

Adjournment: The meeting was adjourned.

Items for Follow-Up:

- Page 4, lines 19-21: Does outreach at hospitals differ from outreach at CBOs when staff are attempting to re-engage clients in care?
- Page 4, lines 19-21: Are any agencies in Queens funded for the return to care initiative?
- Page 4, lines 32-36: Reminder to NA Committee Members: in the formal needs assessment, we need to discuss the impact of interventions to address structural barriers such as medical homes, Medicaid managed care, and SNPs, as well as the changing landscape associated with health care reform.
- Page 4, line 45 through page 5, line 2: Caps on services: this topic will be discussed in other committees, and the outcome of the discussion will be shared with NA Committee members.