Meeting Minutes

NEEDS ASSESSMENT COMMITTEE

Jennifer Irwin, Chair

Monday, May 12, 2008
9:30 am-11:30 am
GMHC, 119 West 24th Street, Room 410

Members Present: Angela Aidala, PhD, Lenore Hildebrand, DSW, Jennifer Irwin, Rebecca Kim, Rosemary Lopez, Jan Carl Park, Howard Schwartz, JD, Ricardo Vanegas-Plata, DDS

DOHMH Staff Present: Rafael Molina, Nina Rothschild, DrPH, Anthony Santella, DrPH, Ellen Wiewel, Darryl Wong

Others Present: Myron Gold, Marcelo Soares, Jacqueline Whitehead

Materials Distributed: Agenda; minutes from the previous meeting of the NA Committee on April 1, 2008; new PSRA tool and explanatory notes; annotated guide to data sources; list of CHAIN reports; CHAIN study conceptual variables; CDC epi/surveillance slides on racial/ethnic distribution of HIV/AIDS in the US.

Introductions/Welcome: Members introduced themselves. Ms. Irwin welcomed the members and provided an overview of the meeting, noting that she had asked Committee members to prepare a list of gaps/emerging needs and research issues and to come to the table for a discussion about data requests to inform the Planning Council's Priority Setting and Resource Allocation Committee. She stated that the NA Committee would meet again in June and possibly in July and that we want to wrap up this planning year with some concrete deliverables and to think ahead to 2009. The HIV/AIDS epidemic, she commented, has changed a lot in ten years, and we need to examine what's relevant now and what needs to be redone.

Review of the Meeting Packet: Nina Rothschild reviewed the contents of the meeting packet.

Update on the Priority Setting Tool with a Focus on Emerging Needs: Dr. Anthony Santella explained that the PSRA tool is used for programming and for reprogramming. He explained how the new tool differs from the previous version and noted that the weight for the consumer priority criteria has increased slightly. When the PSRA Committee meets again on June 5th to rank the service categories, it will use the Payer of

Last Resort tool (commissioned from the New York Academy of Medicine) and information from the recent consumer focus groups to guide its decision-making process. Although the points and the weights are different in the revised PSRA tool, the tool itself is not a radical departure from the instrument used in the past.

Update on Consumer Focus Groups: Dr. Santella also provided an update on the five consumer focus groups recently convened by DOHMH. A total of 40 individuals participated, and the information is currently being analyzed. Rosemary Lopez inquired whether DOHMH went outside Manhattan to recruit clients and noted that 40 is a relatively small number of participants. Dr. Santella responded that focus group members included individuals from all five boroughs, although the groups took place in Manhattan at Cicatelli because of accessibility, and that the goal was to have 8-10 people per group (although the actual number of participants in the youth group was smaller). He also noted that the focus group guide was modeled on the CAB survey. Mr. Gold spoke positively of the focus group in which he participated, noting that it really engaged in good work. Focus groups in other languages are a possibility for next year. The Planning Council also has other consumer data at its disposal, including a CHAIN study and a Maintenance in Care survey currently being conducted at four sites in the Bronx, Manhattan, and Brooklyn.

Discussion of Emerging Needs and Research Questions: Needs Assessment Committee members engaged in a lively discussion of emerging needs and mentioned the following populations:

- Homeless and street-walking transgender individuals who cannot be served in programs for MSM
- Youth prostitutes and people who are injecting themselves with various materials including caulking and are buying hormones on the street and sharing needles
- Youth who are aging out of the foster care system
- Disabled individuals who have trouble accessing services
- HIV-infected immigrants (37% of the population is foreign-born)
- Incarcerated immigrants and detainees
- Individuals who have problems with their immigration status and do not seek out care
- Individuals who have been infected in situations of conflict and war (war rapes in countries such as the Sudan, Liberia, and the Ivory Coast)
- Human trafficking victims, particularly individuals from Eastern Europe
- Migrant workers
- Uninsured individuals
- Individuals over 50 years old
- Women of color and young women of color
- Adults and youth released from jail/prison
- Substance users, especially users of crystal methamphetamine

Group members identified numerous difficulties associated with providing services to people infected with or at risk for HIV. Ms. Lopez noted the problems associated with trying to obtain funding for some groups whose total numbers are small. Dr. Angela Aidala noted the increasing number of co-morbidities such as diabetes and cardiovascular disease in the HIV-infected population, as well as the problems that arise because physicians and other treatment providers who specialize in these co-morbidities may not have vast experience in treating the HIV-positive population, and she referred to the need for linkages between different parts of the treatment system.

Mr. Soares mentioned the problems associated with closing the bathhouses: sex clubs are under scrutiny, and individuals may turn to private parties where unsafe activities occur. Dr. Vanegas-Plata responded to Mr. Soares's comment, noting that the US is the only country in the world where the bathhouses have been closed, and closing the bathhouses simply means that the activity goes underground. He also cited the problem of stigma. Dr. Aidala noted that CHAIN already collects a small amount of data on stigma and that a separate study of people who are not in care shows that these individuals don't want the stigma of being identified as a PWA. In addition, Dr. Aidala stated that prior experiences with the medical care system may keep some people out of treatment; an individual who experienced stigma as an MSM or as a woman with multiple children by different fathers may be reluctant to engage. Another example of a health care system problem was cited by Ms. Whitehead, who mentioned that ERs do not provide any privacy.

Dr. Vanegas-Plata noted the impact of religious and social issues on conducting HIV/AIDS-related work, commenting that the Catholic Church says no to condoms and that societies with a strong emphasis on machismo also create an atmosphere in which condoms are unlikely to be used. Another problem with conducting HIV/AIDS work is the insularity of some immigrant groups, who fear that word will leak out into their home community that they are HIV-infected. Some immigrant groups also seek out alternative, non-traditional healers, whose work may interfere with conventional treatment.

Mr. Park mentioned the gap in services created by the closing of three clinics on Staten Island. Patients who have been seen in these facilities (roughly 350-400 of whom are HIV+) will be referred elsewhere for treatment and care, but we don't yet know whether they will be able to obtain treatment on the Island or will have to go to another borough. Ms. Lopez cited another problem related to provision of services: agencies funded by the Planning Council who are not able to maintain their performance-based contracts because they were given only a 6-month start-up period are having to give back some of the money they received with their contracts. Mr. Park noted that services contracted out by the Health Department have to be evenly distributed throughout the City, and that a gap may arise if an agency cannot fulfill its contract. He also noted that DOHMH's master contractor, Public Health Solutions, does re-examine unfunded proposals as it prepares to address any gaps.

Needs Assessment Committee members also discussed the potential impact if the HIV Care Networks are restructured: some individuals rely on the Care Networks, and a restructuring may affect service delivery. Some Care Networks have already closed

down, and the remaining networks have to do more with less in the face of funding cuts. Mr. Soares raised another problem associated with reduced service delivery, noting that oral health services in the City were already affected by the closing of Bellevue's dental clinic and that services were further reduced when a dental clinic affiliated with a hospital in Hell's Kitchen was shut down when the hospital closed.

Prison releasees constitute another population whose complex needs provide a challenge to service providers. Mr. Park noted that the Health Department already does discharge planning for people who are leaving prison, and the Planning Council will listen to a presentation on this topic at its next meeting. Ms. Kim mentioned the problems associated with releasing people from jail who do not know that they are infected. Mr. Park noted that the Health Department funds The Osborne Association and Fortune Society, both of which work with jail/prison releasees, but we can only help these folks if they avail themselves of the assistance that is offered. Dr. Hildebrand mentioned a related issue – namely, the manner in which prison staff respond to individuals who are known to be HIV-infected.

Ms. Irwin turned to Dr. Aidala and Ms. Wiewel to ask how Needs Assessment can obtain data on some of these issues. Dr. Aidala responded with a brief update on research projects in the CHAIN pipeline. A report on client satisfaction will be released, and this report also examines why people drop out of care. The CHAIN study includes transgender individuals, but only a small number. The CHAIN study includes individuals who are over 20 years old, but no adolescents. A CHAIN report on PLWHAs over 50 has been written. Ms. Irwin stated that she would ask Dr. Nancy Van Devanter about research on HIV and youth. Mr. Park noted that DOHMH's Epi and Surveillance Program includes a staff member who focuses on pediatric and adolescent HIV. Dr. Hildebrand stated that the PPG has a transgender advisory group. Mr. Park noted that studies exist on all these issues and that the goal for the Planning Council and the Committees is to ensure that programs address the needs of each of these populations. Ms. Irwin suggested determining which agencies serve these various populations, bearing in mind that some populations are very difficult to engage and maintain in care. Dr. Hildebrand stated that grass roots agencies are just trying to survive, as are their clients, who may not present with HIV-related needs because other needs take precedence.

Dr. Santella turned to Ms. Wiewel, whose office receives records of the approximately 100,000 people living with HIV and AIDS in the City. Ms. Wiewel noted that the information collected by her unit of the Health Department is different from CHAIN's data. Her unit collects information about age, race, ethnicity, sex, borough, neighborhood, and country of birth. The unit tries to collect information on transgender individuals, but the information obtained by the HIV Epi Program is only as good as what is in the medical chart. She noted that the HIV Epidemiology Program also does research studies such as the House Ball Study (a population of 60+ individuals who were born male but identify as women). The Field Services Unit, a branch of the HIV Epidemiology Program, interviews people who are newly diagnosed and includes a questionnaire that elicits more detailed information than the data obtained solely from medical charts.

Dr. Santella guided the conversation toward the PSRA Committee meeting on June 5th, noting that all these populations and issues will stay on the radar screen. He suggested prioritizing the populations and then seeing what data we have on them from CHAIN and from the HIV Epidemiology Program. Mr. Park commented that all these populations are being serviced, but we don't know whether the services fully meet their needs. Needs Assessment Committee members settled on several priority populations, including young MSM of color, LGBT individuals, women of color and young women of color, immigrants, and individuals over age 50. Needs Assessment Committee members also prioritized several service gaps, including housing services, the Staten Island and dental clinic closures, and re-entry programs for prison releasees.

Public Comment: Mr. Gold stated that staff at some agencies could benefit from sensitivity training.

Next Meeting: The Needs Assessment Committee will meet again on June 11th from 3:00-5:00.