



CONSUMERS COMMITTEE

Wednesday, February 16, 2011 1:00 – 3:00PM

Hispanic Federation, 55 Exchange Place, 5th Fl. Conf Rm , New York, NY

Planning Council Members Present: Victor Benadava (Co-Chair), John A. Eddie (Co-Chair), Gerald DeYounge, Alexander Hardman, Keith Kaiman, Deborah Marcano, Pastor Jerome Payne

Planning Council Members Absent: Brent Backofen, Felicia Carroll, Kareem Clemons, Steve Hemraj, Munying Hunt, Kali Lindsey, Hilda Mateo

Community Members Present: Gregory Cruz (Consumer At-Large), Manuel Ducret III, Colombia Fierro, Stewart Fogel, Yves Gebhardt, Johnny Guaylupo, Joseph Ogun, Mallory Marcus, Glen Phillip, Manuel Rivera, Joseph Sellman, Escott Solomon, Rick Thurmond, Jacqueline Williams

DOHMH: Rafael Molina, Darryl Wong

Guests: Mark Brennan, PhD., Stephen Karpiak, Ph.D. (ACRIA)

MEETING MATERIALS DISTRIBUTED:

- Meeting Agenda;
- Planning Council Ground Rules of Respectful Engagement/Rules for Public Comment;
- January 19, 2011 Draft Meeting Minutes;
- Morbidity & Mortality Weekly Report (MMWR), Interim Guidance: Pre-exposure Prophylaxis for the Prevention of HIV Infection in Men Who Have Sex with Men, January 28, 2011, Vol 60, No 3;
- ADAP Watch List, NASTAD, January 2011;
- CAEAR Coalition, Action Alert: Urge Congress Not to Cut the Ryan White Program this Year
- Positive Voice, NAPWA Newsletter, January 28, 2011, Ser 2, Vol 1, Issue 20
- Growing Older with HIV, ACRIA/ACHIEVE, Fall 2009
- Complications of Success: HIV & Aging, Presentation by Stephen Karpiak, PhD and Mark Brennan, PhD, AIDS Community Research Initiative of America (ACRIA), NY, NY
- February 2011 Planning Council Calendar & Month at a Glance

INTRODUCTIONS:

The Co-Chairs welcomed participants, including newly-appointed Committee members, Randall Bruce, Kenneth Butler, Johnny Guaylupo, Glenn Phillip, Rick Thurmond, Jacqueline Williams and Planning Council member Deborah Marcano. John Anthony-Eddie led the moment of silence and the meeting participants reviewed the Rules of Respectful Engagement.

Darryl Wong reviewed the meeting agenda and meeting materials. The minutes of the January 2011 meeting were reviewed and approved, with changes noted, as follows. Manuel Rivera repeated that some individuals, due to health concerns, may have been unable to submit applications, but that certain individuals should be exempt from this application process given their long standing in the HIV/AIDS community. Pastor Payne suggested that the audiotapes of the

meeting should serve as the official transcript of the meeting. Escott Solomon clarified that the Consumer Involvement Committee of the Manhattan HIV Care Network has been inactive

PUBLIC COMMENT:

Joseph Sellman expressed his personal dissatisfaction, as well as on behalf of other long-time advocates who were not appointed to the Consumers Committee and questioned the transparency of the overall Committee appointment process. Mr. Rivera also raised his concern regarding the Committee appointment process, noting that the Governmental Co-Chair has sole discretion regarding Committee appointments. He also cited the grievance procedures which are available to members of the public to register complaints.

PRESENTATION: HIV& AGING/SUCSESSES & COMPLICATIONS

Drs. Stephen Karpiak and Mark Brennan of the AIDS Community Research Initiative of America (ACRIA) began their presentation by noting the dramatic increase of over 100,000 AIDS cases in people over 50 years from 1995 -2005, adding that the CDC predicts that within five (5) years, 50% of all PLWHAs will be over 50 years of age. In New York, City, of the ~ 120,750 PLWHAs, 40% are over age 50 and 75% are over age 40. Data is presented from the 2006 comprehensive study, Research on Older Adults with HIV (ROAH), with 1000 NYC older adults having participated, spanning areas from demographics and sexual behavior to HIV stigma and disclosure. The following are highlights of the presentation:

- Almost 1/3 of the participants were female, nearly 3/4 were Black or Latino, and 80% were in their 50's;
- The health co-morbidities, conditions and social isolation issues cited in ROAH are generally found in much older populations;
- Over 2/3 of ROAH participants identified as heterosexual, most were on disability, were US born and had educational levels similar to those seen Citywide;
- Whites accounted for the highest proportion of those with an AIDS diagnosis;
- Across the board the percentages of those on ARV therapy were high (~85% and higher);
- While unprotect vaginal and anal sex and needle sharing were the most common transmission modes in PWAs who have been diagnosed > 10 years, unprotected heterosexual (vaginal) sex is the highest reported transmission mode for diagnoses less than 5 years;
- Most participants received their treatment in public clinics/hospitals and 83% of ROAH participants are Medicaid dependent;
- Most PWAs disclosed to their healthcare providers (90.5%) compared to co-workers (36.4%) or places of worship (35.4%);
- 30-43% of participants expressed wanting to disclose their status to someone else but were reluctant to do so;
- The average number of co-morbidities among this study's participants is three times the amount reported in the general elderly 70+ population; the service related implications beg further discussion;
- Approximately 30% of the sample reported co-morbidities such as hepatitis, neuropathy, dermatological and well over 50% reported depression;

- Visual and hearing impairments were more often reported in this study population, compared to the general population;
- ACRIA, the American Academy of HIV Medicine and the American Geriatric Society have been involved in discussing and planning for multiple morbidities case management;
- 84% of study participants have a history of tobacco use, with 57% currently reporting tobacco use;
- The most commonly used substances include alcohol, marijuana, painkiller, heroin, crack and cocaine, all of which can interfere with ARV therapy (pharmaco-kinetically, as well as with treatment adherence);
- Social networks are a significant healthcare resource; caregivers are derived from social networks;
- 70% of participants reported living alone (compared to 39% of elderly 65 year olds + New Yorkers), with only 14% reporting living with a partner or spouse;
- While siblings and friends comprise the most often cited available supports, friends are the highest functional supports (actually available and in contact) for study participants;
- Fragile social networks, as represented by reports of loneliness are higher for older adults with HIV than for older adults in general;
- Those in an integrated network reported the least amount of loneliness (UCLA score) compared to those who were isolated;
- Severe depression was commonly reported (43%), associated with loneliness and social isolation (self or by rejection); depression is the single primary predictor of non-adherence;
- Hispanics report higher levels of depression; and
- A once-a-week intervention (phone call to check in) markedly decreased the course of depression over 20 weeks.

In the past, HIV disease management has been approached in silos. The synergistic natures of multi-morbid conditions place great emphasis on organ systems at risk and thus cannot be treated isolation; they must be treated in relation to each other. Complex guidelines will be released this Summer. A mainstreaming approach, combating stigma (HIV & gender) should be coupled with ongoing research to develop interventions serving older populations. Data from studies such as ROAH can be used to inform the development of service delivery guidances, which are the basis of future RFPs.

ANNOUNCEMENTS:

The Manhattan HIV CARE Network will be meeting on Wednesday, March 9. There are still openings for several trainings in the LTI Planning Council training series; those who have taken the trainings have found them to be informative and useful in understanding HIV service and community planning.

ADJOURNMENT:

There being no further business, the meeting was adjourned at 3:30PM.