



## **CONSUMERS COMMITTEE**

Tuesday, June 16, 2015, 1:00 – 3:30 PM

LGBT Community Center, 208 West 13<sup>th</sup> Street, Rm 101, New York, NY

**Planning Council Members Present:** David Martin (Co-Chair), Billy Fields (Co-Chair), Randall Bruce (Consumer At Large), Saul Reyes

**Planning Council Members Absent:** Lotus Blackman, Altirik Harper, Harry Jackson, Jesus Maldonado, Carlos Rosario

**Appointed Community Members:** Felicia Carroll, Jose Colon-Beredecia, Glen Phillip

**Guests:** Mark Browne, Russell Stevens, John Schoepp

**NYCDOHMH:** Eric Rude, Darryl Wong

### **MEETING MATERIALS DISTRIBUTED:**

- Meeting Agenda/Planning Council Ground Rules of Respectful Engagement;
- May 19, 2015 Meeting Minutes;
- HRSA Notice of Award FY15
  
- NYCDOHMH HIV/AIDS Bi-Weekly Update, June 2, 2015;
- Planning Council New Member Application;
- Announcement of the Governor's Plan to End AIDS, April 29, 2015;
- Recommendations from Blueprint to End AIDS;
- Bending the Curve: Can New York End Its AIDS Epidemic?, Futterman & Jackson, 1/8/15, The Body;
- HIV/AIDS & Hepatitis C in NYC – State of the Diseases and Barriers to Care;
- Hep Free NYC June 2015 Newsletter;
- HIV Treatment Should Start at Diagnosis, US Health Officials Say, McNeil, D., 5/27/15, NY Times;
- Update: Invasive Meningococcal Disease in MSM, NYC Health Alert # 11, 6/12/2015;
- LGBT Health Digest, June 11, 2015, Gay & Lesbian Medical Association;
- National Working Positive Coalition: Recommendation to Update Employment Provisions in the National HIV/AIDS Strategy, May 20, 2015;
- AIDS United, The Power of Positive Voices, Webinar Announcement, June 30, 2:30-3:30PM;
- May 2015 Meeting Evaluation Results;
- June 2015 Meeting Evaluation Form; and
- June and July 2015 Planning Council Meeting Calendar.

### **WELCOME/INTRODUCTIONS/REVIEW OF MINUTES**

*David Martin and Billy Fields, Co-Chairs of the Committee opened the meeting, followed by participant introductions. Felicia Carroll, led the group in a moment of silence in honor of friends and colleagues who have passed recently. The Rules of Respectful Engagement, meeting agenda and meeting packet were reviewed. The May 2015 minutes were accepted by acclamation; the April 2015 minutes were not accepted, as indicated in the May minutes, and will be reviewed in July.*

**PUBLIC COMMENT:** There was no public comment.

**PRESENTATION: HIV/AIDS & HEPATITIS IN NYC – STATE OF THE DISEASE AND BARRIERS TO CARE**

Darryl Wong introduced Eric Rude, MSW, Director of Viral Hepatitis Policy and Development at the NYCDOHMH, who briefly presented on the epidemiology of HCV for PLWHA in New York City with the goal of addressing the barriers for Ryan White clients in accessing medications. The following points were noted:

- 60-70% of those infected with HCV will progress to chronic liver disease
- HCV is exacerbated by alcohol use and HIV co-infection
- Approximately, 1-5% will die from chronic HCV due to liver cancer or cirrhosis
- Of the estimated ~150,000 infected with HCV, about half are aware of their infection; of those, approximately 10,000 have been treated and 5,000 have been cured of HCV in NYC
- The highest rates of HCV are in the South Bronx, Lower Manhattan (due to use of zip code of General Post Office by the homeless population, Staten Island, Lower Brooklyn, Central Queens and Upper Manhattan
- Of the approximately 150,000 persons with HIV, 16% are HIV/HCV co-infected, 71% male, median age 39, 43% Black, 42% Hispanic, 14% White and 0.5% API. 60% of those co-infected report injecting drug use for HIV transmission category
- For the Ryan White population, of ~20,000 individuals, 24% had HCV
- 21% of Ryan White clients accessing Mental Health services and 33% of Harm Reduction clients had a prior HCV report
- HRSA has defined a service category known as a Local Pharmaceutical Assistance Program (LPAP) which can help Ryan White clients obtain some medications that may not be on the ADAP formulary
- 32 other cities have LPAPs, which negotiate directly with pharmaceutical companies
- The Planning Council will identify and quantify need for such medications and will begin to address disparities
- The new generation HCV drugs are not on the New York State ADAP formulary because of their high cost
- The old generation HCV meds are on the ADAP formulary, but the new PEG-interferon-free regimens are available only through private insurance or Medicaid, with restrictions on access to HCV medications;
- HCV cure rate for individuals co-infected with HIV and HCV who receive the new medications is between 96 and 100%
- Different insurance companies have preferred drugs
- Patient has to demonstrate readiness to adhere to the drug regimen and must be abstinent from illicit drugs/alcohol for 6 months to 1 year
- Baseline HCV RNA must be submitted
- Patient must be stage 3 or 4 fibrosis
- Patients who are co-infected with HIV must have an undetectable HIV viral load
- Medicaid's restrictions on access for HIV patients are not based on medical evidence and should be removed.
- All of the new HCV meds are on the Medicaid formulary, but patients who have fee-for-service Medicaid can only have Viekira Pak.
- NYC DOHMH is participating in a demonstration project, Project Inspire, with the Center for Medicare and Medicaid Services (CMS) with the aim of reducing costs using a care coordination model.
- Some patient assistance programs (available through pharmaceutical companies) cover co-pays and some cover deductibles.
- HRSA, our Ryan White federal funder, does not allow us to use Early Intervention Services (EIS) dollars for HCV testing – but we can cover HCV awareness when discussing health promotion topics and can do directly observed therapy (DOT) for HIV and HCV medications.

- Although we can only use Ryan White funding to pay for the components of medical care covered by Medicaid, we may not be bound by the same restrictions that Medicaid places on access.
- Thirty-two (32) local pharmaceutical assistance programs in this country
- Community members should engage in advocacy around the issue of profiteering by pharmaceutical companies and place pressure on them to lower prices. The Planning Council's Policy Committee could advocate regarding the restrictions associated with viral load.

### **NY PLANNING COUNCIL /CONSUMER COMMITTEE UPDATES**

Darryl Wong updated the Committee on the recently Notice of Grant Award for FY15. The NY EMA received a cut of 1.7% or \$1,825,270, due to the reduction in formula funding for our EMA. The scenario plan and ranking of services was used to determine the range of cuts to each service category. The NY EMA received a score of 99, which documents need, interventions, unmet need and gaps in service.

The *PSRA Committee* will review the entire portfolio and the service category ranking system in the Fall of this year.

The *Integration of Care Committee* has approved the Early Intervention Service Directive and was recently approved by the Planning Council. The Legal Services Directive is next in line for review. Since we are able to develop the directive guided by locally determined needs, the IOC committee is meeting tomorrow to finalize and approve, if applicable, this directive. All legal services must be HIV related in nature in order to be included in the directive

The *Needs Assessment Committee* will host a half-day community briefing, which will include graphic and informational briefs.

The *Rules and Membership Committee* is continuing its discussions on the absorption of the Tri County Steering Committee and will be reviewing Planning Council new member applications.

### **NYS BLUEPRINT FOR ENDING THE EPIDEMIC IN NY**

David Martin requested that the meeting be extended so that the blueprint on Ending the Epidemic (ETE) can be addressed. Concurrently, a presentation from Housing Works on the End of the Epidemic is taking place at the LGBT Center in Room 301.

Billy Fields identified Blueprint recommendations to be discussed in greater detail. Felicia Carroll suggested that the Committee attend the ETE presentation in Room 301, as one of the Co-Chairs of the Task Force of the Blueprint will be presenting each recommendation in greater detail.

### **PUBLIC COMMENT/NEW BUSINESS/BOROUGH UPDATES**

Saul Reyes shared his comments on the NYCDOHMH epidemiologic studies on the Transgender population in NYC from 2005 – 2009 and 2008-12 and is interested in current or future studies being/ to be done. Darryl Wong suggested that the July 2015 meeting might focus on HIV Stigma and Discrimination. David Martin referenced the previous month's Consumers Committee, at which the CHAIN study on Needs and Utilization was presented and there was expressed dissatisfaction at the omission of the transgender population in the demographic analysis of the study cohort. Mr. Wong advised that comments be sent to Planning Council staff Nina Rothschild, who sits on the Technical Review Team (TRT) for CHAIN. A request was made that, in the future, comments be offered in a more professional, constructive and non-confrontational manner.

### **ADJOURNMENT**

There being no further business, the meeting was adjourned.