



**CONSUMERS COMMITTEE**  
Thursday, May 22, 2013, 1 – 3:30PM  
NYCDOHMH, 42-09 28<sup>th</sup> Street, Conf Rm 14-31  
Long Island City, NY

**Planning Council Members Present:** Victor Benadava (Co-Chair), Randall Bruce (Consumer-At-Large), Lotus Blackman, Muying Hunt, Deborah Marcano

**Planning Council Members Absent:** Victor Alvarez (Tri-County), Gregory Cruz (Co-Chair), Gerald DeYounge, Rev. Keith Holder, David Martin, Tracy Neil, Pastor Jerome Payne

**Appointed Community Members Present:** Billy Fields, Glen Phillip, Yves Gebhardt, Joey Lopez,

**Guests:** Priscilla Bright, Donna Classe, Donald Coble, Damon Grandison, Mallory Lowenstein, Peter Messeri, PhD., Mark Misrok, Dwon Myers

**NYCDOHMH:** Rafael Molina, Jan Carl Park, Darryl Wong

**MEETING MATERIALS DISTRIBUTED:**

- Meeting Agenda/Planning Council Ground Rules of Respectful Engagement;
- April 17, 13 Draft Meeting Minutes;
- 2013 NY EMA Planning Council 2013 Borough-Based Consumer Listening Sessions Flyer;
- CHAIN Presentation: Employment & Economic Wellbeing 2012-4, Peter Messeri & Maiko Yomogida, Columbia University Mailman School of Public Health;
- Part A Consumer Advisory Board Survey, Progress as of October 2011, NY HIV Planning Council;
- Summary of Evaluation of Ryan White Part A-funded HIV/AIDS Programs' CABs in NYC, 7/12;
- NYCDOHMH HIV/AIDS Weekly Updates, May 17, 2013;
- Hepatitis C – A Silent, Worsening Healthcare Crisis in NYC, Jay Varma, MD, MPH, NYCDOHMH;
- NYCDOHMH Health Alert # 12: Updates on Measles in NYC, 5/21/13;
- Federal AIDS Policy Partnership (FAPP) 5/17/13 request for Ryan White consumer impact;
- NYS Statewide AIDS Service Delivery Consortium (SASDC) 2012 Consumer Survey;
- May & June 2013 Planning Council Citywide Listening Sessions Announcement;
- NY HIV Planning Council May & June 2013 calendars.

**WELCOME & INTRODUCTIONS:**

Victor Benadava, Co-Chair, opened the meeting and members introduced themselves. Lotus Blackman led the group in a moment of silence, beginning with the group review of the Rules of Respectful Engagement and followed by the review of the agenda and meeting materials by Darryl Wong. Having received no modifications or revisions, the minutes from the April 2013 meeting were approved.

**CHAIN REPORT: EMPLOYMENT & ECONOMIC WELL-BEING 2012-4:**

Peter Messeri, Ph.D., Professor of Clinical Sociomedical Sciences at the Columbia University Mailman School of Public Health described the CHAIN (Community Health Action Information Network) Project and methodology. CHAIN Data are collected through structured interviews we conduct with PLWHA in all five NYC Boroughs and the Tri-County Region. The NYC Cohort was recruited in 2002 and has completed seven rounds of interviews. The 8<sup>th</sup> round will begin shortly. In 2009-10, additional participants were recruited, with sample sizes ranging between 500 and 700. The Tri County cohort has been active since 2001-2007. Since 2008, the project has continuously recruited and interviewed 125 to 150 individuals per year, with a sample bias towards older populations. Salient highlights from the presentation follow:

### **Major questions of the study aim to ascertain:**

- What are recent trends in current work experience for CHAIN cohorts?
- Among the unemployed, what are reasons for interest and disinterest in returning to work?
- What are recent trends in household income?
- What are the financial needs for CHAIN cohorts?
- How are demographic, human capital and health variables related to current employment?

### **Specific questions related to employment and income that were included in the interview:**

- Are you currently working in a paid position, part time or full time?
  - Most participants, in both cohorts, are not employed; ~ 17% in NYC are currently employed (~6% work full time) in comparison with ~25% in the Tri-county region (~13% work full time).
- What kind of work do you do?
- Are you thinking about or planning to get a job/go back to work? Reasons for and for not thinking about returning to work.
  - In NYC, over 50% of the sample in not interested in working, compared to 40% in Tri-County.
- Multi-item question on sources of income and categories of yearly personal or household income.

### **Reasons “for Thinking/not Thinking about Getting a Job Right Now”**

- Most frequent reasons for thinking about getting a job right now are financial and psychological;
- Most frequent reason for **not** thinking about getting a job right now is poor health;
- Lack of job skills/education and fear of loss of benefits are much less frequently mentioned reasons for not working.
  - Several consumers noted that loss of entitlements benefits acts as a deterrent to employment

### **Income and Poverty**

- NYC cohort (2009-2011): Median household income \$7.5K - \$10K / 61% under the poverty line
  - *Unemployed* - Median household income \$7.5K-\$10K/65% under the poverty line
  - *Employed part-time* - Median household income \$10K-\$15K/34% under the poverty line
  - *Employed full-time* - Median household income \$25K-\$35K/22% under the poverty line
- Tri-County cohort (2010-2012): Median household income \$7.5K - \$10K / 52% under the poverty line
  - *Unemployed* - Median household income \$7.5K-\$10K/57% under the poverty line
  - *Employed part-time* - Median household income \$10K-\$15K/46% under the poverty line
  - *Employed full-time* - Median household income \$25K-\$35K/6% under the poverty line

### **Financial Need**

- 57% in NYC (2009-2011) and 73% in Tri-County (2010-2012) reported lacking money to pay for one or more of seven household expenses (in the most recent round);
- Cohort members most often mentioned not having enough money to pay for clothing and recreation followed by food, utilities and rent;
- In contrast, few mention lacking money for medical care;
- Financial need was consistently more widespread in the Tri-County than in the NYC cohort.

## **Key Findings**

- Cohort members live economically precarious lives;
- Employment remains stubbornly low: Less than a quarter of CHAIN participants employed, and for most of the employed, work is irregular;
- Approximately half the current CHAIN cohort is not thinking about getting a job;
- Employment is higher among the Tri-County than the NYC cohort, even so, half of all Tri-County live in households with earnings below the federal poverty level;
- Tri-County residents were more likely than NYC residents to report has lacking money at times for a variety of household expenditures;
- Health and human capital are key factors associated with current employment.

## **Policy Implications**

- Can we distinguish individuals with truly disabling health conditions and those whose health status may improve by appropriate medical care and mental health interventions?
- What are options for job training & rehabilitation that are best suited for HIV+ individuals interested work?
- Are there work environment and job positions may be well suited for the special needs and skills of HIV+ employees?
- How do PLWHA define what it means to live productive lives?

## **COMMUNITY ADVISORY BOARD (CAB) BEST PRACTICES SURVEY:**

The 2011 Community Advisory Board (CAB) survey findings were reviewed with the Committee and a workplan for developing recommendations to agencies in enhancing their CAB outreach, engagement, input, feedback and process guidelines was proposed. It was suggested that at the June meeting the Committee break into small workgroups of 4-5 persons in order to address themes/findings related to CAB functioning, including 1) coordination, 2) cohesion/conflict management, 3) team effectiveness, 4) team meeting communication and 5) team meeting leadership. Each workgroup will be charged with developing recommendations based on best practices related to the thematic set of questions. These recommendations will be presented to the Executive Committee and ultimately to Public Health Solutions for possible inclusion in CAB monitoring and documentation activities during the contract negotiation and/or renewal processes. The Committee will invite Rachel Miller of Public Health Solutions to the July meeting.

## **PLANNING COUNCIL CONSUMER LISTENING SESSIONS:**

Although there has been widespread dissemination of the Consumer Listening Sessions throughout the City, the attendance at the Queens, Staten Island and Bronx sessions has been disappointing. Members are encouraged to assist in outreach efforts.

## **PUBLIC COMMENT:**

Yves Gebhardt reported that 1) there was a presentation on HIV criminalization in NYS by the HIV Law Project, 2) the Bronx HIV CARE Network would be meeting on the 23<sup>rd</sup>, 3) Mayoral Forums are scheduled in Manhattan at el Museo del Barrio and at Hunter School of Public Health and 4) the announcement of the listening sessions has been forwarded to over 900+ individuals on the Manhattan CARE Network list-serve. Today marks the 30<sup>th</sup> anniversary of the announcement of a “lymphadenovirus (LAV)” among gay men by the Institut Pasteur.

Victor Benedava, Co-Chair of the Committee announced his resignation from the Consumers Committee and from the HIV Planning Council, effective immediately.

## **ADJOURNMENT:**

There being no further business, the meeting was adjourned at 4:00PM.