



CONSUMERS COMMITTEE

Thursday, June 18, 2014, 1:00 – 3:30 PM

NYCDOHMH, 42-09 28th Street, Room 17-42, Long Island City, NY

Planning Council Members Present: David Martin (Co-Chair), Billy Fields (Co-Chair), Randall Bruce (Consumer At Large), Rev. Keith Holder, Deborah Marcano, Pastor Jerome Payne,

Planning Council Members Absent: Victor Alvarez (Tri-County), Lotus Blackman, Felicia Carroll, Kareem Clemons, Muying Hunt, Antonio Munoz, Tracy Neil, Saul Reyes

Appointed Community Members: Jose Colon-Berdecia, Yves Gebhardt, Ron Joyner, Joey Lope, Glen Phillip

Guest Speakers: Melissa Baker, Cinthia Castro, Emma Roberts, Leatrice Wactor, Adisa Yamusah

NYCDOHMH: Rafael Molina, Jan Carl Park, Nina Rothschild, DrPH, Darryl Wong

MEETING MATERIALS DISTRIBUTED:

- Meeting Agenda/Planning Council Ground Rules of Respectful Engagement;
- May 21, 2014 Meeting Minutes;
- ACT-UP: The Atlanta Principles, 6/14;
- Health Resources Services Administration (HRSA) HIV/AIDS Bureau Part Objective Review Committee – Final Summary Statement, June 2014;
- Changes to NYS HIV Testing Law; NYSDOH letter & Key provisions, 5/2/14;
- NY State of Health Enrollment Guidelines for Health Exchanges;
- NYCDOHMH HIV/AIDS Weekly Update, 6/13/14;
- NY HIV Planning Council, Home and Community-Based Health Services Service Directive, 6/6/14;
- Harlem Hep C Task Force, Meeting Highlights, June 2014;
- NYC Hep C Task Force, Bronx Chapter, 7/16/14 Meeting Announcement;
- HIV and Viral Hepatitis, CDC, 3/14;
- Hepatitis A, B and C: Learn the Differences, IAC, 8/12;
- SMART/COPE Hepatitis C University Educational Flyer;
- HIV/HCV Co-Infection: HIV Infection doesn't really matter anymore, D. Kotler, 6/14;
- Hepatitis C: A Public Health Approach, F. Laraque, 6/14;
- Hepatitis resolution is passed at the World Health Assembly, Treatment Action Group, 6/14;
- Defuse Hepatitis C, the Viral Time Bomb, Position Paper for the World Health Assembly, 5/14;
- Hepatitis C: Quick Reference Guide, www.HepBC.org;
- Hepatitis C: The Facts, NYCDOHMH;
- Chronic Hepatitis C Rate (2012) by neighborhood, NYCDOHMH Epi Query
- Check Hep C & Treatment at Harlem United, 2014;
- Mobile Health Program, Flyer, Harlem United, 2014;
- National African American Hepatitis C Action Day – July 25, 2014, National Black Leadership Commission of AIDS, Inc.;
- Consumer Committee May 2014 Meeting Evaluation Results;
- Consumer Committee June 2014 Meeting Evaluation; and
- June & July 2014 HIV Planning Council Meeting Calendars.

WELCOME & INTRODUCTIONS

David Martin and Billy Fields, Co-Chairs of the Committee opened the meeting, followed by a moment of silence and member and guest introductions. The Rules of Respectful Engagement, the meeting

47 agenda and materials were reviewed. The minutes from the May 21 meeting were accepted as
48 presented.
49

50 **CONSUMER PERSPECTIVES ON HOME & COMMUNITY-BASED HEALTH SERVICES**

51 Nina Rothschild, DrPH, HIV Planning Council staff to the Integration of Care Committee, presented the
52 draft service directive for Home & Community-Based Health Services (formerly Home Care) to the
53 Consumers committee for their feedback and input. As this service category has not been re-bid for
54 quite some time and is the lowest ranked service of twelve (12) service categories (with funding of ~\$1
55 million), consumers of home-care service were asked to reflect on their experiences with home care
56 services after having reviewed the program directive and service model, as well as client and agency
57 eligibility:

- 58 • What services are provided by the Ryan White funded portion of the program?
- 59 • What gap does the program fill for HIV/AIDS patients?
- 60 • What is the medical eligibility for clients who receive Ryan White home-based services? Are all
61 clients homebound?
- 62 • How are positive health outcomes, resulting from the delivery of home-based services,
63 measured?
- 64 • How do these services coordinate with Medicaid-funded services?
65

66 A summary of comments and input/feedback follows:

- 67 • *All home care attendants are not trained to work with visually-impaired individuals' challenges and
68 living situations;*
- 69 • *There is a lack of monitoring attendants' quality of work, including safety, security and theft
70 concerns; clients may feel inhibited in reporting adverse events for fear of retaliation;*
- 71 • *There is a wide variety of workers in a home care environment - home health aides, personal care
72 attendants and nurses, who perform different tasks for the home-based client; coordination of
73 services remains an ongoing challenge;*
- 74 • *Due to large caseloads, some agencies are less responsive to clients' concerns;*
- 75 • *Language barriers and lack of meal preparation skills are challenges;*
- 76 • *With the reduced frequency of nurses' visits, care plans are not followed rigorously;*
- 77 • *Agencies are not routinely notifying clients of changes in staffing within a 24 hour period.*
78

79 It was noted that upon hospital discharge, services are not always well-coordinated; a patient advocate
80 role has been discussed for possible inclusion in the service model. Consumers with additional
81 comments were asked to forward them to either Dr. Rothschild or Darryl Wong.
82

83 **HEPATITIS C – PREVENTION, SCREENING, TESTING & TREATMENT MANAGEMENT**

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85 *Ms. Nirah Johnson, the Director of Program Implementation & Capacity Building in the Viral Hepatitis
86 Surveillance, Prevention & Control Program at NYCDOHMH presented an overview of the Agency's
87 activities. The NYC Hep C Task Force (www.NYCHepBC.org) is a Borough-based community coalition
88 of providers, consumer advocates and clients who are interested in mobilizing, integrating and
89 increasing access to Hepatitis C prevention, screening, testing and treatment activities in NYC.
90*

91 About 145,000 persons in NYC are infected with Hepatitis C (usually chronic, due to the long term
92 nature of the disease). Of the ~115,000 PLWHAs in NYC, approximately 16% (or 18,400 individuals)
93 are infected with Hepatitis C. Those who are co-infected with HIV and Hep C should be in care as soon
94 as possible; all those with HIV should be tested for Hep C. The new Hep C testing law is targeted
95 towards the Baby Boomer generation (those born between 1945-65). 70% of those with Hep C are
96 unaware of how they acquired the infection. The greatest number of cases are for chronic Hepatitis C;
97 new cases are among youth who are transitioning from prescription drug use to injecting drug use.
98

99 Those who are treated and cured of Hepatitis C can no longer transmit Hep C. About 25% of those
100 infected with Hep C can clear the virus without medication; both the antibody and confirmatory tests
101 are required to document infection and should be encouraged to support follow up and treatment
102 activities. Current treatment regimens include interferon and ribavirin; more promising treatments

103 (Solvadi by Gilead) are expected within a year. Consumers are encouraged to participate in their
104 local Hep C Task Forces.

105 *Adisa Yamusah, Hep C Program Coordinator at Harlem United* briefly reviewed the etiology and
106 epidemiology of Hepatitis C. There are particular challenges with treatment. The specific medications
107 used and the duration of treatment depend on a number of factors, including HCV genotype, past
108 treatment experience, eligibility to take interferon and whether the person is waiting for a liver
109 transplant. Clients are treated with Solvadi, while co-infected clients are treated with a combination of
110 Solvadi, Ribavirin and pegylated interferon. Treatment can vary depending on various factors such as
111 treatment & adherence readiness, HIV viral load and whether or not client has been previously treated.
112

113 An initial Hepatitis C appointment is arranged with their medical staff, who will perform a full medical
114 workup, including liver functioning. A lifestyle/mental health screening will address the client's
115 biographical history, past drug use and mental health issues. During this initial appointment, clients
116 may be referred for additional testing and services, including nutritional services, sonograms,
117 psychiatric referrals and substance abuse counseling.
118

119 *Emma Roberts, Director of the Mobile Health Program at Harlem United*, described the challenges and
120 successes in engaging individuals into the program, especially for those who have undergone several
121 failed treatment regimens and who are actively using injectable drugs. The mobile clinic contains two
122 exam rooms, where medical and dental care is offered and serves clients from a holistic perspective.
123 The mobile van serves Coney Island, the Bronx, Bedford Stuyvesant in Brooklyn and Harlem on
124 rotating days. Dental services are offered on a sliding scale.
125

126 *Melissa Baker and Leatrice Wactor of the National Black Leadership Commission on AIDS*, spoke to
127 mobilization of communities, bringing awareness to affected communities and advocating for greater
128 action. Through their partnership with COPE and the Harm Reduction Center, NBLCA will co-sponsor
129 the second African American Hepatitis C Awareness Day on Friday, July 25. Four recommendations
130 from a recent Hepatitis C consensus paper have been embraced by NBLCA for action: 1) increase
131 awareness, 2) address the need for physicians to revise screening processes, 3) African American
132 participation in HCV clinical trials and 4) addressing health disparities in affected communities. Other
133 challenges include engaging faith-based communities in the dialogue, physician/medical team
134 training and garnering political will to secure funding to screen, test and treat those who may be
135 affected.
136

137 **HIV PLANNING COUNCIL UPDATES**

138 The ACT-UP Atlanta Principles were distributed for reference. This document makes several
139 recommendations to the CDC with regard to HIV prevention messaging, treatment as prevention
140 (TASP), PrEP and PEP, HIV prevention funding, HIV testing and testing guidelines, HIV epidemiology,
141 behavioral surveillance, sex education and continued partnerships with HIV-affected communities.
142

143 The May 2014 meeting evaluation results were distributed, noting that meeting start/end times, agenda
144 structure, meeting location remained challenging for some participants. There was significant positive
145 feedback on the usefulness of the issues (Federal, State and local HIV care continuums and results of
146 the 2013 consumer listening sessions) discussed at the meeting.
147

148 Committee members were reminded that the Planning Council new member recruitment process is
149 underway and that applications are due to NYCDOHMH by late June. Applications were distributed at
150 the meeting and are available through www.nyhiv.org.
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152 **PUBLIC COMMENT:**

153 There are continuing challenges for consumers accessing the private health insurance marketplace.
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155 **ADJOURNMENT:**

156 There being no further business, the meeting was adjourned at 3:45PM.
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