



## **CONSUMERS COMMITTEE**

Monday, July 16, 2012, 12:00-2:00 PM

AIDS Service Center of NYC, 41 East 11<sup>th</sup> St., 5<sup>th</sup> Fl., New York, NY

**Planning Council Members Present:** Victor Benadava (Co-Chair), , Randall Bruce, Sharen Duke, Muying Hunt, Deborah Marcano

**Planning Council Members Absent:**, Gregory Cruz (Co-Chair), Victor Alvarez, Felicia Carroll, Gerald DeYounge, John Eddie, Steve Hemraj, Rev. Keith Holder, Hilda Mateo, Pastor Jerome Payne

**Community Members Present:** Delores Henley, Matthew Lesieur, Mallory Lowenstein, David Martin, Jacqueline Williams

**DOHMH:** Rafael Molina, Nina Rothschild, Darryl Wong

### **MEETING MATERIALS DISTRIBUTED:**

- Meeting Agenda/Planning Council Ground Rules of Respectful Engagement;
- June 20, 2012 Draft Meeting Minutes;
- HRSA Announcement: Public Input Sought on Ryan White Reauthorization;
- HRSA Ryan White Reauthorization Listening Sessions Schedule;
- Discussion Points – How will the Ryan White Program fit into the ACA in 2014?
- [NAPWA Applauds Supreme Court Decision Upholding the Affordable Care Act](#), NAPWA Press Release, 6/28/2012;
- [Rapid HIV Home Test Wins Federal Approval](#), NY Times, 7/3/12
- [Approval of first In-Home HIV Antibody Test](#), FDA Communication, 7/23/12;
- [FDA Treads Carefully with PrEP](#), The Lancet, 6/28/12
- [HIV/AIDS Semi Annual Report](#), Vol. 7, No.1, April 2012, HIV Epidemiology & Field Services, NYCDOHMH;
- Quality Management 101 Training Announcement, NYSDOH, AIDS Institute, 7/12/12;
- HIV/AIDS Weekly Update, 7/2/12 & 7/13/12;
- [Positive Voice](#), Series 2, Vol. 3, Issue 7, July 2012, National Association of People with AIDS;
- POZ Magazine, July/August 2012

### **INTRODUCTIONS:**

Victor Benadava, Co-Chair opened the meeting. Muying Hunt led the Committee in a moment of silence. Darryl Wong reviewed the agenda and meeting materials. Although there was a lack of quorum, the minutes of the June meeting were approved by acclamation.

### **PUBLIC COMMENT:**

There was no public comment.

### **HRSA – RYAN WHITE RE-AUTHORIZATION PUBLIC INPUT**

Darryl Wong opened the discussion by providing the Committee with overarching questions to help frame consumers' comments on the value of Ryan White services:

- How will the Ryan White program fit into the Affordable Care Act when it is fully implemented in 2014?
- How can Ryan White best fill in gaps in services not covered by the Affordable Care Act?
- Where will Ryan White program clients get care in 2014?
- How do we create/maintain a health care landscape/environment that keeps people in care?

<b>VERY LOW INCOME INDIVIDUALS with INCOME &lt; \$15,000 (138% FPL)</b>	<b>INDIVIDUALS EARNING between \$15,000 &amp; \$44,000 (138% to 400% FPL)</b>	<b>PEOPLE WHO CAN NOT ENROLL IN HEALTH CARE REFORM PROGRAMS</b>
Eligible for Medicaid based on income alone	Purchase private insurance with premium tax credits and cost-sharing subsidies	Ryan White will be a safety net for legal immigrants not eligible for Medicaid (5 year ban) & undocumented immigrants
Ryan White will fill gaps <b>not</b> covered by Medicaid	Ryan White will fill gaps <b>not</b> covered by private insurance	

A brief discussion of factors related to the implementation of the Affordable Care Act and its effect on Ryan White services follows:

- Full impact of Affordable Care Act may not be fully apparent for years after 2014. Locally, in NYC, Medicaid Health Homes have not yet been fully implemented, nor have all clients been transitioned from care coordination programs to health homes. As a result, we do not yet know the full impact of ACA on service provision locally;
- There is the need for maximum flexibility in order to fill unanticipated gaps, especially during new years of coverage;
- Mechanism(s) for Ryan White to sustain core health services must be considered until coverage is established;
- Care coordination should be promoted in order to prevent gaps in services not traditionally provided by Medicaid (Housing services, legal services, supportive counseling & family stabilization);
- Funding for patient navigation in ACA is insufficient for transition needs for PLWHA;
- Need for services where Ryan White care integrates with basic medical services;
- The changing health care landscape must work with & support the existing network/inventory of Ryan White providers who have been delivering care & providing navigation services for > two decades;
- A response plan for populations that will remain ineligible for coverage under Health Care Reform must be developed;
- The Affordable Care Act & Ryan White Care program must be aligned in order to make progress toward National HIV/AIDS Strategy (3) major goals:
  - **Reduce** new infections & **Increase** % of people who know their status
  - **Increase** access to care & **Improve** Health outcomes for PLWHA
  - **Reduce** HIV-related health disparities

### **CONSUMERS' PERSPECTIVES ON RYAN WHITE SERVICES**

Consumers then shared their individual perspectives and experiences with Ryan White services in New York City, citing the following personal testimonies:

#### *Food & Nutrition Services:*

- “Food & nutrition programs have gotten me into care & treatment”
- “Food & nutrition programs taught me how to cook & how to stay healthy”

#### *Mental Health Services:*

- “Mental health services helped bring me back”
- “Mental health services helped me stay sober and be healthier”

*Legal Services:*

- “Legal services helped me get my kids back because I had no place to live”
- “Legal services helped me declare bankruptcy & to regain financial stability”

*Care Coordination:*

- “Care coordination is essential for those [of us] without homes, education and the wherewithal to find services”
- “Care coordination helped me find services”

*Ryan White Services (general):*

- “Ryan White has given me access to mental health counseling, psychiatric visits and medications to treat my depression”
- “Ryan White provides an array of services – meeting me where I’m at”
- “Ryan White helped me to take care of myself and my family”
- “Ryan White helped me to regain my sanity”
- “Being homeless, a drug addict, taking me off the streets...Ryan White gave me a second chance in life”
- “Ryan White services for women helped include me in the conversation”

*Consumer Involvement/Peer support:*

- “Opportunities for consumer involvement and training helped me not to feel useless and to make a difference”
- “Peer support services helped me to not feel alone and to feel taken care of”

*Unmet needs:*

- Vocational education and rehabilitation

The ensuing discussion focused on the benefit of recommending an extension of the Ryan White HATEA, rather than a full reauthorization. The following points were articulated:

- The current political climate, particularly in the House of Representatives, is relatively hostile to HIV/AIDS constituencies. If reauthorization is sought, the struggle is likely to be difficult. Pursuing an extension, rather than a full reauthorization, may be safer, politically;
- A full reauthorization process might call attention to the fact that Ryan White is the only payer of care for the undocumented population;
- In 2014, when the Affordable Care Act is fully implemented, there will be more data about the impact of health care reform on HIV/AIDS services. There will be a better sense of what gaps remain and how Ryan White can best meet those unmet needs;
- A reauthorized CARE Act could include a modification of the current 75%/25% core medical/non-core support services split. The split could, for example, become 85% core/15% non-core – potentially impacting negatively on services such as housing and food and nutrition which are vital to accessing and remaining in care;
- A reauthorized CARE Act could eliminate Planning Councils and add additional target populations such as Hepatitis C patients, potentially drawing funds away from PLWHAs.

Members were thanked for their input, which will be used as the basis for the letter to be sent to HRSA regarding extension.

**BOROUGH UPDATES: HIV NETWORKING ACTIVITIES/PUBLIC COMMENT/ANNOUNCEMENTS:**

AIDS Service Center of Queens County is sponsoring a bus with VOCAL to the International AIDS Conference in Washington, DC. for one day. The Staten Island Network will be meeting in July. Depending on the timing of Planning Council new member appointments, there may be a meeting in September.

**ADJOURNMENT:**

There being no further business, the meeting was adjourned at 3:00PM.