HIV HEALTH & HUMAN SERVICES
PLANNING COUNCIL OF NEW YORK
A Mayoral Council established by the Ryan White C.A.R.E. Act of 1990

CONSUMERS COMMITTEE

Wednesday, April 18, 1-3:30PM

NYCDOHMH, Gotham Center, 42-09 28th Street, Room 8-25, Long Island City, NY

Planning Council Members Present: Victor Benadava (Co-Chair), Gregory Cruz (Co-Chair), Randall Bruce, Felicia Carroll, Rev. Keith Holder, Munying Hunt

Planning Council Members Absent:, Victor Alvarez, Gerald DeYounge, John Eddie, Steve Hemraj, Rev. Keith Holder, Deborah Marcano, Hilda Mateo, Pastor Jerome Payne

Community Members Present: Delores Henley, Joey Lopez, David Martin

DOHMH: Rafael Molina, Darryl Wong

MEETING MATERIALS DISTRIBUTED:

- Meeting Agenda/Planning Council Ground Rules of Respectful Engagement;
- February 15, 2012 Draft Meeting Minutes;
- March 21, 2012 Draft Meeting Minutes;
- 2012 Planning Council Member Application;
- Breakin' It Down: What the Affordable Care Act Means for People With HIV Powerpoint;
- Six Ways the Affordable Care Act will help People with HIV, www.HIVHealthReform.org;
- Take Action on Health Care Reform, www.HIVHealthReform.org;
- Healthcare Reform Monitoring Project – HIV/AIDS Community Update, April 2012;
- NYSDOH AIDS Institute Quality Improvement 101 training announcement;
- National Quality Center: in+care Campaign; NYSDOH AIDS Institute Powerpoint;
- In+care campaign brochure;
- NYC/AIDS Weekly Update, 4/13/12;
- HASA Facts, March 2012, nyc Human Resources Administration;
- ADAP Watch, April 13, 2012, NASTAD;
- Many Men with Undetectable HIV in Blood Still have Low Levels in their Semen, AIDS Map.com;
- The Graying of HIV, HIV Plus Magazine;
- Clinical Research Study A1438011 Announcement, Bristol-Meyers Squibb
- May 2012 NY HIV Planning Council Meeting Calendar

INTRODUCTIONS:

Gregory Cruz and Victor Benadava, Co-Chairs opened the meeting and members introduced themselves. Felicia Carroll led the Committee in a moment of silence. Darryl Wong reviewed the agenda and meeting materials. Due to the lack of quorum at the March 2012 meeting, the minutes of the February meeting could not be approved; the minutes of both the February and March 2012 meetings were reviewed and approved, as presented.

PUBLIC COMMENT:

There was no public comment.

WEBINAR PRESENTATION I: WHAT THE AFFORDABLE CARE ACT MEANS FOR PEOPLE WITH HIV: BREAKIN' IT DOWN

Due to technical difficulties, this webinar was unable to be viewed. However, a summary of main points derived from the Powerpoint slide set appears below:

The relationship between health care reform and the National HIV/AIDS Strategy was underscored through the presentation of the strategy's three main goals: reducing new infections, increasing access to care and improving health outcomes for PLWHAs and reducing HIV-related health disparities.

Currently, 28% of PLWHAs are uninsured and 34% are enrolled in Medicaid; it was noted that even those with private insurance have challenges in meeting cost-sharing obligations. Outpatient, acute care and prescription drugs expenditures for PLWHAs are 50% to several hundred percent higher than for those not living with HIV/AIDS. While HIV/AIDS caseloads have risen steadily, funding since 2001 has remained relatively flat. In addition, ADAP waitlists approaching 4,000 nationally, high demand for Ryan White services and from 42% and 59% of low income PLWHAs not in regular care are contributing factors to the current crisis.

Pre-existing condition Insurance Plans (PCIP) are now available in every state, some run through the State and some through a federally-administered plans. Created under the Affordable Care Act (ACA) to ensure that Americans with pre-existing conditions can access affordable health insurance, 24 ADAP programs (a/o 12/11) can help pay PCIP insurance premiums and have enrolled 2,393 clients.

In 2014, most low-income people will be eligible for Medicaid, through expansion of eligibility criteria. The disability requirement will be eliminated for most people with incomes up to 133% of FPL , which is currently ~ $14,000 for an individual and ~$29,000 for a family of four. With this expansion are state-determined Essential Health Benefits for those newly-eligible, as well as enhanced reimbursement for primary care providers. Affordable Care Act Essential Health Benefits include: ambulatory services, emergency services, hospitalization, maternity/newborn care, mental health and substance use disorder services, prescription drugs, rehabilitative and habilitative services, laboratory services, preventive and wellness services and chronic disease management and pediatric services. Services need by PLWHAs not fully covered by Medicaid include dental services, non-medical case management, nutrition services, transportation, mental health services, peer support services and insurance assistance. Medicaid will not be available to undocumented individuals or undocumented immigrants and legal immigrants within the 5 year ban.

Beginning in 2014, consumer-friendly health insurance exchanges to purchase private insurance will be created, with no lifetime or annual limits on coverage and eliminating the possibility that health plans can drop people from coverage when they become ill or increase premiums based on gender and health status. Federal subsidies will be available for those with income up to 400% FPL, or ~$44,000 for an individual and ~$89,000 for a family of four. Plans must include Essential Health Benefits and must contract with community providers, including Ryan White programs.

Through the Medicaid Health Home Program, enhanced and coordinated care is now an option for those living with chronic medical conditions, including PLWHAs. Medicare will provide a 50% discount on all brand-name prescription drugs, ADAP contributions swill now count towards copayments and the Part D donut-hole will be phased out by 2020, improving access to prevention/screening services.

With respect to the Supreme Court challenge to the Affordable Care Act, it is important to acknowledge that the issues of individual mandate and Medicaid expansion may be challenged with the justification that Congress has broad power to regulate interstate commerce, including health insurance. Medicaid expansion is constitutional in that Medicaid expansion has been changed and expanded many times in history and that no expansion in the past has ever been found to be unconstitutional.

WEBINAR PRESENTATION II: CONSUMER INVOLVEMENT IN QUALITY IMPROVEMENT:

SHARED PERSPECTIVES FROM PROJECT HOSPITALITY

This Webinar was hosted by the NYS DOH AIDS Institute's National Quality Center Quality Academy and focused on experiential learning in quality improvement and engagement of consumers in Quality Management/Improvement issues, as well as identification of perceived barrier and challenges, from the perspective of Project Hospitality, a harm reduction service provider.

Different ways to involve consumers and to support consumer engagement include consumer advocacy, engagement in QM/QI programs, patient-centered HIV care and self-management approaches. With consumer advocacy, patients understand their illness and how to help clinicians with treatment decisions, have QM plans that include written standards for consume involvement and care that is patient centered and delivered in a non- judgmental atmosphere.

Historically, quality improvement (QI) models used in health care were created for the automotive industry. A critical dimension of QI is determining consumer needs as well as developing products and services that meet and exceed customer expectations. QI practices have been adapted for use in health care settings, although many medical disciplines are still grappling with how and to what extent they should involve consumers.

Two dimensions of quality address provider and consumer perceptions: providers have a certain perception of the quality of HIV care (the technical aspect) and consumers have their own perceptions based on their experience with the health care system with which they interact. In order to improve care and services, there needs to be focus on both elements through shared partnerships, as they are inter-connected.

Consumer support includes raising awareness of quality improvement/management issues, providing training to build capacity, providing regular and routine input, formalizing the input and evaluating the effectiveness. Activities related to these goals include:

1. **Routinely solicit input from consumers who receive HIV primary care by:**
    - Conducting satisfaction surveys, focus groups, or patient interviews to gather ideas for improvement from the consumer perspective
    - Clearly defining and prioritizing ideas for improvement and share with staff and patients for feedback
    - Discussing key findings during QM committee meetings
    - When appropriate, forming a consumer advisory committee (CAC) to routinely solicit feedback on the goals of QI activities, methods of data collection, and what will be done with the results through agency-wide QI activities
    - Engaging the CAC and/or a broader patient population in discussions about key findings and areas for improvement

2. **Implementing QI activities that are reflective of the needs of those receiving HIV primary care services:**
    - Engaging PLWHA when planning QI activities such as selecting annual QI goals or prioritizing clinical performance measures
    - Routinely presenting HIV clinical performance data results to consumers
    - Explaining and discussing routine performance data reports with consumer representatives and solicit their recommendations when planning next steps

3. **Formalizing the engagement of PLWHA to actively participate in QI activities and support them in this process:**
    - Nominating and appointing appropriate consumers as equal members on QI teams to identify and improve aspects of HIV care
    - Developing skills-building and training opportunities for consumers so they can fully participate in agency-wide HIV QM committees and QI teams
    - Building further understanding among HIV staff about the benefits of engaging consumers in QI activities
    - Linking QI activities of the HIV QM program with CAC discussions

4. **Routinely informing consumers of evolving QI activities via multiple communication venues and media:**

- Openly sharing the results of QI activities, including performance data results and updates from quality improvement projects, with all patients via displays in the waiting room, storyboards, or newsletters
- Informing consumers about facility-wide QI activities and in doing so, highlighting their role in improving key aspects of HIV care
- Celebrating and publicizing the successes of consumer involvement in QI activities among patients and staff

5. **Annually assessing the programmatic level of consumer involvement across the entire HIV agency:**

- Developing and/or adopting a standardized assessment tool to evaluate the level and effectiveness of consumer involvement
- Conducting this assessment annually and discuss the results with the quality management committee
- Responding to the findings and make adjustments moving forward

The Project Hospitality Harm Reduction Program strives to provide counseling and education regarding reducing the risks associated with substance use and abuse, sexual activity, intravenous drug use, HIV and/or Hepatitis C, medical treatment plan adherence, etc.

The program's QI Team identified areas for improvement according to results from the 2010 Annual Consumer Satisfaction Survey. The survey focused on clients' perception of several core elements: support, efficacy, professionalism, dignity, comfort, cultural sensitivity, competence, **reliability,** trust, and equity.

One question from the 2010 Consumer Satisfaction Survey,"*In an emergency do you feel confident that staff will be there for you to resolve the problem?"* received a positive response of only 71% of those surveyed. It was decided that the goal was to improve clients' perception about the program's reliability to a minimum of 85%, as clients' perceptions may impact levels of engagement and retention into services. In order to assess clients' perceptions of services, the program created mini satisfaction survey instrument, bi-weekly ongoing meetings were conducted by the Harm Reduction Team to discuss issues, the Program Director started providing monthly focus groups/community meetings at the site as part of the regular group program (minutes are sent to the QI Dept), helping assure that clients' concerns and barriers to meeting clients' needs were addressed by staff both on an individual and group level.

As a result of clients' feedback and contributions, issues affecting clients' perceptions about program's competence include lack of clarity about HR Program services from part of service providers, lack of clear expectations about program services and demands and lack of proper orientation about the benefits of comprehensive services.

In order to increase harm reduction service promotion staff should be encouraged to educate clients about HR services and increase level of knowledge about the program, each HR team member should be introduced to the client at the time of the intake, awareness and knowledge about the Harm Reduction staff availability should be increased to help instill trust and continuous focus groups should be implemented to identify clients' barriers.

An improvement strategy was developed, which created a welcoming environment and easy access to services for all within the continuum of substance use, and assess clients' needs frequently. The team created a post card to introduce the Harm Reduction program's services and team to all clients. This idea was tested and according to the program's 2011Customer Satisfaction Survey, the number respondents whose perceptions about the program's reliability increased to **94%.**

Perceived client barriers (from the providers' perspective) include disclosure risk, lack of understanding of quality management principles, competent staff is overburdened, lack of time and availability to maintain commitment, over-focus on issues that cannot be changed or inappropriate/personal issues, oppositional personalities, lack of current knowledge regarding current clinical guidelines/practice and overall lack of interest in quality improvement.

Lessons learned from this Quality Improvement activity included:

- Seeing things from the **clients' perspective** can be very valuable.
- **Continuous staff involvement** is key to promoting new services and educating clients about programmatic changes.
- **Collaboration with other programs** within the agency (COBRA Case Management, Mental Health, Supportive Counseling, Drop-in Center) to promote and educate clients about HR services and staff availability is required.
- **Process evaluations can often be helpful** to reveal information about team work, clients' perceptions and solutions to problems.
- Contributing factors to the improvement/change: **Staff feedback** was given to the QI Dept to redesign the annual survey. Questions were revised to remind consumers exactly which program they were responding about. **Definitions of services and satisfaction elements were also clarified.** Coincidentally, the same number of consumers filled out the survey during both years, but it is unknown if they were the same exact consumers. It is possible that these factors may affect the reliability of the calculated change.
- Cast a wide net to recruit
- Orientation [e.g. consumer education program, member education activities]
- Assure that there are clear expectations – [e.g. advisory role, information you are seeking, how information will be used, provide a *real* task, what the group *is* AND what it *is not*]
- Value and balance expertise/data with experience/individual & anecdotal
- Use of correct language and terminology
- Prepare for and hold everyone to the same confidentiality standards
- Facilitate participation, e.g. schedule, out-of-pocket costs
- Use the information; explain how it is used or why it is not

The **benefits of enhanced consumer involvement** in quality management are many:

- Bridges the gap between perceived & actual needs of clients
- Promotes greater communication
- Decisions/changes become more credible
- Challenges the status quo
- Increases accountability
- The greater the diversity in QI, the harder it becomes for a single perspective/philosophy to guide actions
- Identifies service barriers and issue seen by providers
- Informs outreach, and most importantly,
- Improves self-care and care advocacy for others

BOROUGH UPDATES ON HIV NETWORKING ACTIVITIES:

There was a Borough update for Staten Island.

PUBLIC COMMENT/ANNOUNCEMENTS

There was no public comment.

ADJOURNMENT:

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