Planning Council Members Present: Lisa Best (Co-Chair), Billy Fields (Co-Chair), Saul Reyes (Consumer At Large), Atif Abdul-Haaq, Randall Bruce, Paul Carr, Maria Diaz (Co-Chair, Tri County Steering Committee), Charmaine Graham, Justin Li Greci, Monique Mackey, Malaya Manacop, David Martin, John Schoepp

Planning Council Members Absent: Asia Betancourt, Rose Chestnut, Jesus Maldonado

NYCDOHMH: Jose Colon-Berdecia, Jan Carl Park, Kristina Rodriguez, Darryl Wong

Other: Lauren Schecter (A/V)

MEETING MATERIALS DISTRIBUTED

- Current Meeting Agenda & Minutes of September 25, 2018 meeting
- Power of Quality Improvement Conference Announcement – November 19, 2018
- Consumer at Large Position Description
- Consumer at Large Ballots, 2018-19
- PLWHA/Consumer Participation: HRSA/HAB Expectations and Best Practices, EGM Consulting
- Ryan White Part A Planning Council Primer, May 2018
- NY HIV Planning Council Consumers Committee ByLaws description (draft)
- NY HIV Planning Council Consumers Committee Outreach brochure, 2018
- NY HIV Planning Council Consumers Committee Member Contact List, 2018-19
- NY HIV Planning Council Bylaws, 12/21/17
- New York EMA Quality Management Program, Kristina Rodriguez, NYCDOHMH, QM Program
- NYCDOHMH Bureau of HIV Weekly Updates 10/16/18
- Announcement: ETE by 2020 – A New Approach to Transgender Health Care and Human Rights II, November 15, Queens Museum, 5:30 -9:30PM
- Announcement: 2018 ETE Summit, Dec 4-5, 2018, Albany, NY
- NYCDOHMH Press release: Health Department Expands Initiative to Educate Primary Care Providers about Naloxone, 10/23/18
- "Transgender” Could be Defined out of Existence Under Trump Administration, Green, Benner and Pear, NY Times, 10/21/18
- At Rallies and Online, Transgender People Say They #Won'tBeErased, Mervosh & Hauser, NY Times, 10/22/18
- Career Power Source: Getting Work You Want, October 3, 2018 Exhibitor Table Handouts & Info
- Consumers Committee September 2018 Meeting Evaluation
- Consumers Committee October 2018 Meeting Evaluation
- POZ Magazine, October/November 2018
- November 2018 Planning Council Calendar
WELCOME/INTRODUCTIONS

Billy Fields and Lisa Best, Consumers Committee Co-Chairs, opened the meeting with member introductions and a review of the Rules of Respectful Engagement. New members Charmaine Graham, Monique Mackey and Malaya Manacop were introduced to the Committee and encouraged to express themselves. The minutes from September 25 were approved as presented and the meeting materials were reviewed. A moment of silence was observed in honor of Janet Weinberg, long-time AIDS activist and committed advocate of the rights of those living with disabilities, who passed away on September 1, 2018.

PUBLIC COMMENT

Given the number of issues to be addressed in today’s agenda, the Co-Chairs deferred the first public comment period until the end of the meeting.

2018 -19 CONSUMER AT LARGE ELECTION

The election of the 2018-19 Consumer at Large was declared open. Saul Reyes was nominated, declared his interest in running for this position and was the sole candidate on the slate. Consequently, Saul Reyes was elected Consumer At Large by acclamation.

HIV PLANNING COUNCIL CONSUMERS COMMITTEE ORIENTATION

As a follow-up to the 2018-19 Planning Council new member orientation, Darryl Wong presented a modified PLWH/consumer training developed by former HRSA consultants Emily Gantz McKay and Hila Berl. Topics covered included the history of consumer involvement, legislative requirements of consumer PLWH participation, HRSA expectation for PLWH participation, Committee roles and financial support issues.

Consumer involvement and decision-making is a core component of Ryan White HIV/AIDS Program Part A planning and decision-making. The legislative requirement that 33% of Planning Council members be un-aligned consumers helps assure PLWH into needs assessment and community planning. It is the expectation of HRSA that the consumer voice on Planning Councils and committees be strong, independent, trained/informed and respected. Decision making should focus on the use of consumer data and interactions between the Planning Council and the Grantee must be mutually respectful in accordance with legislative intent and Codes of Conduct.

2009 Legislative requirements state that each Part A planning council should reflect in its composition the demographics of the population of individuals with HIV/AIDS in the area involved, with particular consideration given to disproportionately affected and historically underserved groups and subpopulations. Among the groups that must be represented on the planning council are representatives of “affected communities, including PLWH, members of a Federally-recognized Indian tribe as represented in the population, individuals co-infected with Hep B or C and historically underserved groups and subpopulations: and “individuals who formerly were Federal, State or local prisoners”.

Other legislative requirements for PLWH input state that priority setting and resource allocations (PSRA) must be based on “priorities of the communities with HIV/AIDS for whom the services are intended”. In addition, the Planning Council must establish methods for obtaining input on community needs and priorities which may include public meetings, conducting focus groups and convening ad-hoc panels [all of which the NY EMA Consumers Committee has done].

The Health Resources Services Administration (HRSA) expects that Part A programs maintain full and meaningful (trained and informed) PLWH participation with a focus on consumers of Part A services. Grantees are expected to encourage funded providers to obtain consumer input through community advisory boards (CABs) or other consumer input mechanisms or strategies. Planning Councils are expected to broadly recruit consumer members using an open nominations process, provide
appropriate orientation and training, support continued consumer engagement and ensure that the PLWH membership reflect the epidemic (Parity, inclusion & representation).

**NOTE: The NY EMA/Consumers Committee has achieved all of the above.**

In addition, planning councils should encourage involvement of consumers and other PLWH who are not planning council members by providing a public comment period at each meeting, having a PLWH standing committee open to both planning council members and non-members, encouraging PLWH input into needs assessment through town halls, focus groups, etc., involving non-Planning Council members in appropriate committees, task forces and workgroups, providing regular feedback and information access to the community and engaging consumers in needs assessment.

**NOTE: The NY EMA/Consumers Committee has achieved all of the above.**

Other strategies for actively engaging consumers is the requirement that planning council leadership include consumers, providing and arranging for leadership training for consumers in the community, actively recruiting consumers for task forces, roundtables and reviews of service models, recruiting planning council members from committees or task forces, training consumers a focus group leaders and interviewers for needs assessment and exploring peer community health worker models for Early Intervention Service, Outreach and Medical Case Management.

**NOTE: The NY EMA/Consumers Committee has achieved all of the above.**

The key role of the Consumers Committee is to act as a link between the planning council and the PLWH community. It is best left as a standing committee of the planning council, as opposed to being fully integrated into other standing committees. Recommendations for action are generated by knowledge of the system of care, service gaps and emerging issues.

**ROBERTS RULES OF ORDER (NEWLY REVISED) ORIENTATION**

Joan Corbisiero, Planning Council Parliamentarian, led the group through a pragmatic, outcome-oriented training on the use of Roberts Rules of Order. The guiding principles governing discourse are that everyone has the right to participate in discussion if they wish, before anyone may speak a second time, everyone has the right to know what is going on at all times, only urgent orders may interrupt a speaker, only one thing (motion) can be discussed at a time. The use of motions was discussed and how they may be disposed of (passed, defeated, tabled, referred to committee or postponed indefinitely.

A complete discussion of these rules may be found at: [https://blogs.cornell.edu/deanoffaculty/files/2016/01/RobertsRulesSimplified-1ybt2mk.pdf](https://blogs.cornell.edu/deanoffaculty/files/2016/01/RobertsRulesSimplified-1ybt2mk.pdf)

**QUALITY MANAGEMENT CONSUMER ORIENTATION**

Kristina Rodriguez, Program Coordinator for Quality Improvement began her orientation by referring to the HRSA Monitoring Standards, which are separated into Grantee requirements (there needs to be structured and ongoing efforts to obtain client input in the design and delivery of services) and Planning Council requirements (membership must meet requirements of reflectiveness (i.e. characteristics that reflect the local epidemic). Specific consideration should be given to disproportionately affected and “historically underserved” groups and subpopulations. At least 33% of voting members must be consumers of RWHAP Part A services who are “unaffiliated” or “unaligned.” Of the 15,378 HIV+ clients who were served by the NY EMA Ryan White program in 2017, 88% strict to racial/ethnic minority populations, 70% are enrolled in Medicaid and 20% are uninsured.

The vision of the NY EMA QM Program promotes a comprehensive range of high quality care and treatment by ensuring that medical and supportive services address gaps in the HIV Care Continuum for PLWH in the NY EMA. Services prioritized by the PC support the needs of PLWH and assist them in accessing medical care and adhering to care and treatment, leading to improved care and health across the region. The NY EMA QM Program responds to current challenges in HIV care and promotes the health priorities of PLWH throughout the NY EMA.
The major goals focusing on consumer engagement are as follows:

- Increase & diversify opportunities for consumers to provide timely feedback on service quality & guidance for improving services;
- Improve coordination between NY EMA QM committee & Planning Council consumers committee;
- Increase awareness of biomedical interventions for HIV prevention;
- Improve coordination between providers of clinical care and RWPA-funded service providers.

Quality management activities and methods include coaching for improvement, quality measurement, capacity building & peer learning, assessment & monitoring, technical assistance and Subawardee (contractor) Staff Development and assessing the consumer experience. All Ryan White Part A contractors/sub awardees are required to engage consumers in assessing the quality of services. In addition, the NY EMA QM Program takes a number of approaches to assessing the consumer experience: the Part A Client Experience (formerly ‘Satisfaction’) Survey (CES/CSS), the Community Health Advisory & Information Network (CHAIN) reports and the Planning Council Consumers Committee.

The Client Experience Survey seeks to gather client input and perspectives on RWPA services. Results are utilized by the Care and Treatment Program (CTP), the Planning Council (PC), and RWPA sub awardees for planning and improving HIV services in the NY EMA. The Research and Evaluation Unit (REU) develops the survey with stakeholder input, analyzes the data collected and provides reports to each agency by service category. Results are used to learn about program strengths, weaknesses or gaps, and areas to address for the continual improvement of services delivered. Each agency has access to their own survey data. This assessment of client experience is centralized to gather client feedback in a consistent, comparable manner across programs.

Since 1994, the longitudinal CHAIN cohort study has been conducted with Columbia University’s Mailman School of Public Health to capture the consumer experience with NY EMA services. CHAIN has also served as a foundation for Needs Assessment. To address planning objectives, CHAIN produces multiple policy briefings and reports each year. The CHAIN Technical Review Team (TRT) is composed of multiple CTP staff, PC staff, community members, and representatives from NYS DOH, WCDOH and PHS. All reports are posted to the PC website (nyhiv.org) and many presented to the PC and the community.

Finally, the Consumers Committee of the Planning Council is composed of Planning Council members, as well as unaligned consumers who are not PC voting members. The chairs of the Consumers Committee are active members of the EMA QM Committee and participate in QM Committee activities. The Consumers Committee advises REU on the CES, providing feedback on its development and implementation.

In order to increase & diversify opportunities for consumers to provide timely feedback on service quality & guidance for improving services, quality management activities for 2018 include DOHMH and PHS plans to assess/evaluate consumer engagement models during site visits and attend CAB meetings. In order to improve coordination between NY EMA QM committee & Planning Council Consumers Committee, a consumer-centric presentation will be included in the 2018 Power of QI conference, the quality management program will provide routine updates to the Planning Council in grantee report and the program will provide an orientation and bi-annual updates to Consumers Committee and Planning Council about NY EMA QM program.

**QUALITY IMPROVEMENT CONFERENCE**

Justin LiGreci, Sub Committee Chair for this year’s 2018 consumer presentation invited committee members to join in the development of this year’s workshop.
PUBLIC COMMENT/NEW BUSINESS /ADJOURNMENT

It was noted that there should be a glossary of commonly-used acronyms. The public comment should be used first by members of the public who are not Planning Council members. There should be better coordination to ensure that committee members would be able to participate in the Ryan White webinar which is being screened at the same time as this meeting. The new business item should consistently appear on the agenda. It was noted that there is interest in exploring the topic of HIV and Older persons, especially for persons who have been on medication for 20 years +. It was reported that Public Health Solutions is now requiring all clients to have documentation of HIV+ status. Finally it was noted that the agenda is the vehicle for consumers to determine issues of importance.

There being no further business, the meeting was adjourned at 3:20