

## HIV Quality of Care Consumer Advisory Committee Meeting

55 Exchange Place, New York, NY  
June 13, 2019 | 9:00AM – 12:30PM

AGENDA ITEM/TOPIC	DISCUSSION/ACTION ITEMS
<p><b>Introductions and Announcements</b> <i>Dana Diamond and Leanna Thornton, CAC Co-Chairs</i></p>	<ul style="list-style-type: none"> <li>- Leanna Thornton, CAC-cochair, opened the meeting with introductions. She asked AI members to state why they are motivated to be here today, and asked consumers to state what keeps them coming here.</li> <li>- The varied responses included representation/dissemination of information back to the communities/hearing the voices of the community/to learn about the latest news/educating oneself and their peers/the people themselves/consumer involvement/lack of representation from one’s own group/bringing a voice to marginalized communities.</li> <li>- Dana Diamond, CAC co-chair, called for more attention in the broader community to long term survivors (LTS) and would like to introduce more LTS issues into the agenda.</li> <li>- A dedication was given in honor of Umberto Cruz; his advocacy at the AI helped to create the consumer advisory committee, among many other great feats.</li> </ul>
<p><b>QAC Update</b> <i>Dr. Christine Kerr, QAC Co-Chair</i></p>	<ul style="list-style-type: none"> <li>- Dr. Christine Kerr reported on the events of the most recent QAC meeting in March.</li> <li>- On the QAC agenda, topics included:               <ul style="list-style-type: none"> <li>o 2017 Ending the Epidemic Data Results from Dr. James Tesoriero, AIDS Institute</li> <li>o European Harm Reduction Models from Jason Farrell, European Harm Reduction Network</li> <li>o Harm Reduction in Clinical Practice from Dr. Justine Waldman, REACH Project</li> <li>o Project SUCCEED at BronxCare from Courtney Dower, BronxCare</li> <li>o NYC Health + Hospitals 2017 Cascade from Eunice Casey, Health + Hospitals</li> <li>o 2018 Organizational Cascade Review from Daniel Belanger, AIDS Institute</li> <li>o Amida Care and Value-Based Payments from Doug Wirth, Amida Care</li> </ul> </li> <li>- Dr. Kerr commented that we are starting to see more balance between individual data and big data.</li> <li>- The transition from pay-per-visit to pay-per-performance is being explored and should be given attention.</li> <li>- Michelle Lopez asked if there are any new indicators for the aging with HIV population, i.e. geriatric screenings at a certain age.               <ul style="list-style-type: none"> <li>o Right now, clinicians have just been looking at frailty markers.</li> </ul> </li> <li>- The separation between providers for adolescent and adult care makes it difficult for young adults to transition.</li> <li>- The CAC co-chairs will look closely at the agenda structure going forward to make sure issues discussed today are addressed.</li> </ul>
<p><b>Bylaw Review</b> <i>Dana Diamond and Leanna Thornton, CAC Co-Chairs</i></p>	<ul style="list-style-type: none"> <li>- Leanna Thornton, CAC co-chair, asked for any last-minute amendments or questions before the bylaws are re-ratified due to new membership. An email sent out June 3<sup>rd</sup> asked for amendments ahead of the meeting.</li> <li>- Dan Tietz received an email asking about term limits for the CAC members.               <ul style="list-style-type: none"> <li>o Julian Brown advised against setting term limits due to the difficulty of keeping and gaining new members.</li> </ul> </li> <li>- The bylaws were re-ratified without any amendments.</li> </ul>

<p><b>Quality of Care at Callen Lorde</b>  <i>Boe Ramirez and Pedro Carnelio, Callen Lorde Community Health Center</i></p>	<ul style="list-style-type: none"> <li>- Boe Ramirez, data analyst at Callen-Lorde Community Health Center, presented on how Callen-Lorde’s Consumer Advisory Board (CAB) helps define quality at Callen-Lorde.</li> <li>- Mr. Ramirez described his experience contracting a spinal bacterial infection from a staph infection while receiving care. Providers did not recognize that Mr. Ramirez’s infection was different from HIV. <ul style="list-style-type: none"> <li>o The provider is writing two policy changes based on Mr. Ramirez’s experience. When the policy changes are written, leadership wants to check with Mr. Ramirez before finalizing changes.</li> </ul> </li> <li>- Callen-Lorde’s CAB includes patients and families of patients who meet with management to discuss programs offered. The CAB assesses how effective the service is in terms of safety, fairness, timeliness, and patient-centeredness.</li> <li>- The goal of the CAB is to maximize quality of care for each person’s particular circumstances, make recommendations back to the Callen-Lorde, and obtain commitment from Callen-Lorde to accept their recommendations.</li> <li>- The CAB Quality Dashboard was developed by Callen-Lorde’s CAB and is a partnership between data and quality. CABs should create dashboard reports to present to clinical staff.</li> <li>- After a dashboard is built, CAB should look at measures and look for anything outside the perception of what the CAB believes makes sense.</li> <li>- The dashboard can be used to open conversations about quality in order to improve quality of care.</li> <li>- Mr. Ramirez presented guidance on how to read a dashboard and tips for communicating with CAB organizations. <ul style="list-style-type: none"> <li>o Tips included requesting leadership to attend CAB meetings to discuss concerns and policy, creating presentations for senior management, and informing the organization of the priority of the dashboard.</li> </ul> </li> <li>- Mr. Ramirez will share his presentation with CAC members.</li> <li>- Comments from CAC members: <ul style="list-style-type: none"> <li>o CAC members thanked Mr. Ramirez for providing a framework for CAB members to make changes and encouraging potential CAB members to serve.</li> <li>o Members also suggested that Mr. Ramirez develop the quality dashboard as a tool for others to use.</li> </ul> </li> </ul>
<p><b>Discussion: Re-engaging Stigma and Tobacco Subcommittees</b>  <i>Dan Tietz and Courtney Ahmed, AIDS Institute</i></p>	<ul style="list-style-type: none"> <li>- Courtney Ahmed presented on the results of the NYS DOH Quality of Care program’s staff stigma survey rolled out in 2017. She then opened the floor to recommendations from CAC members for the stigma subcommittee.</li> <li>- Of the 80 health care organizations that received the survey, 50 completed the staff survey and submitted results which were qualitatively reviewed the QOC program. Quantitative results came from 12 of the 50 sites who submitted their results in raw data format. Sites were also asked to obtain consumer feedback on their experiences in the healthcare setting.</li> <li>- Key points: <ul style="list-style-type: none"> <li>o Healthcare workers are reporting that most stigmatizing behaviors are shown toward transgender/gender non-conforming individuals and people diagnosed with mental health disorders.</li> <li>o Surveys revealed an overall lack of training on HIV and key population-related stigma and barriers to health.</li> <li>o About a quarter of survey respondents agreed that infection occurs due to irresponsible behavior, which puts blame on PLWH.</li> <li>o Consumers expressed concern for confidentiality and privacy, lack of knowledge within/inclusion of HIV-negative population.</li> </ul> </li> </ul>

	<ul style="list-style-type: none"> <li>○ Sites' stigma reduction action plans focus on improving staff education, creating a more welcoming and inclusive environment, and consumer involvement via CABs and elicited feedback.</li> <li>- Recommendations from consumers on staff survey: <ul style="list-style-type: none"> <li>○ Survey should be expanded to include the following targets for stigma: people who use drugs, sex workers, condomless sex, immigrants/non-native English speakers, and the homeless population.</li> <li>○ All healthcare workers across organization should take staff survey, not just HIV departments.</li> <li>○ Reporting of staff survey results should be standardized.</li> </ul> </li> <li>- Additional recommendations from CAC members: <ul style="list-style-type: none"> <li>○ Mandate annual training on trauma-informed care.</li> <li>○ Incorporate diverse consumer panels in trainings for new hires; Q&amp;A offers safe space to ask questions and hear consumer perspective.</li> <li>○ Follow up with agencies to find out how they are tackling stigma.</li> <li>○ Address the root causes of stigma during staff trainings.</li> <li>○ Capturing real people's opinions depends on how questions are asked. Looking at other surveys will be helpful. Ms. Ahmed noted that more open-ended questions provide richer insight.</li> <li>○ Follow up with Dr. Nyblade on best practices for stigma reduction.</li> <li>○ Remember that stigma comes from sexual practices, not just HIV; review survey questions.</li> <li>○ Train staff to know how to make consumers feel welcome, not just invited.</li> <li>○ Select an ombudperson for anonymous complaints because people are afraid to speak for fear of affecting service.</li> <li>○ EMR language must be updated because stigmatizing questions are already built in.</li> </ul> </li> <li>- Ms. Ahmed offered to send CAC members materials related to stigma, including the stigma staff survey and a poster on the results of the staff survey.</li> </ul>
<p><b>Discussion: Young Adult Consumer Advisory Committee</b>  <i>Adrian Centeno, YACAC Chair</i></p>	<ul style="list-style-type: none"> <li>- Adrian Centeno, YACAC chair, had to leave early so the YACAC members met privately and shared the results of their discussion with the CAC co-chairs.</li> <li>- A subcommittee is much needed for young adults because their voices are frequently pushed aside.</li> <li>- When Ms. Thornton began serving on YACAC, it focused on advocacy for young adults, not quality.</li> <li>- Current members of YACAC will serve as mentors for new members.</li> <li>- The focus of YACAC will be on viral load suppression, mental health, and advocating on behalf of young adults.</li> <li>- Jahlove Serrano stated that the infrastructure already exists to talk to youth about sex. The conversation about youth needs to be upfront and not at the end. Adolescents are falling out of care, and the best way to prevent people from getting sick when they are older is to reach them when they are adolescents.</li> <li>- Justin noted that perinatally infected individuals have the lowest viral load suppression rate in New York State at 58%. These are priorities that need to be addressed.</li> </ul>

**Engaging Consumers in the Quality Measurement Enterprise**

*Dr. Thomas Concannon,  
Rand Organization*

- Dr. Thomas Concannon, RAND Corporation, presented on consumer engagement in quality measurement.
- RAND is a research organization that develops solutions to public policy challenges. Community Catalyst sponsored RAND to explore concerns of consumer advocates about quality measurement (QM) work.
- Dr. Concannon's team developed a diagram on the life "coil" of a quality measure, which is ongoing:
  - o 1. Setting priorities (e.g. tobacco cessation)
  - o 2. Creating measure concepts (e.g. tobacco screening)
  - o 3. Specifying measures
  - o 4. Testing and endorsing measures (state level)
  - o 5. Using measures to improve the care available to community members
  - o 6. Maintaining measures
- Dr. Concannon pointed out that most often consumers are engaged too late in the process of developing quality measures, when they should be engaged from the beginning.
- RAND strove to articulate barriers from the standpoint of consumers and communicate them to measurement leaders in healthcare.
- Consumers were asked to review and comment on RAND's report containing the QM lifecycle, barriers to effective engagement, recommendations to QM leaders, and recommendations to consumer advocates.
- 6 barriers to effective engagement were found:
  - o "Unequal power": Unlike stakeholders who are paid by organizations, consumers are often unpaid and juggle many outside commitments. Consumer perspectives don't carry equal weight in technical topics like research or statistics.
  - o "Limited menus": Invitations to attend quality measurement processes are often given at the state level, which is way too late because the rigorous processes have already been set. When consumers are invited, they are invited superficially, and they come in with a sense of only the measures that are on the table for that meeting.
  - o "One seat at the table": As few as one or a handful of consumers are typically expected to represent the entire range of consumers in age, race, gender, etc.
  - o "Flat-footed": Consumers brought in are given inadequate time to prepare and respond. Documents are sent for pre-read only 36 hours in advance. Those who are working outside of the organization don't have time for that.
  - o "Closed doors": Back-channel communications that consumers are not privy to are a reality. Sometimes there are conflict of interest issues, but the main point is to call attention to closed-door conversations in order to redress them where possible, so consumers can come prepared to a meeting.
  - o "Dual focus": Consumers are often asked to wade into waters where they lack training or experience. They might have trouble specifying the measure they want to see.
- Recommendations for quality measurement leaders:
  - o Focus national attention on consumer-centered quality measurement.
  - o Assess the extent to which quality measurement processes are open or closed to consumers nationally.
  - o Convene independent and public reviews of quality measurement work.
  - o Build and share knowledge and technical expertise about the process.

	<ul style="list-style-type: none"> <li>- What can consumer advocates do? <ul style="list-style-type: none"> <li>o Right now, there are no consumer representatives focusing on quality measurement of healthcare nationally. Consumers can engage in national conversations and push for research to drive these.</li> <li>o Understand where changes to the system at the ground level are needed. (Clemens Steinbock shared a success story of a former CAB member who was picked up by HRSA.)</li> <li>o Compare quality measurement processes across states and share best practices.</li> <li>o Convene without being asked and conduct independent reviews of quality measurement work.</li> <li>o Make sure consumers arrive understanding the institutional history.</li> </ul> </li> <li>- Comments from CAC members: <ul style="list-style-type: none"> <li>o One member thanked Dr. Concannon and said he “felt the consumer involvement that went into the report” and “didn’t know the power I had.”</li> </ul> </li> </ul>
<p><b>Drug User Health Capacity-Building and Education in New York State</b>  <i>Rob Curry, AIDS Institute</i></p>	<ul style="list-style-type: none"> <li>- Rob Curry, AIDS Institute, presented on the Drug User Health Capacity-Building Initiative (DUH CBI) and new educational materials from the AIDS Institute.</li> <li>- DUH CBI was piloted in 2018 and is based on the principles of harm reduction.</li> <li>- Funded providers were invited to participate. Of the invited agencies, 10 to 12 agencies participated and appointed two champions to participate in the initiative.</li> <li>- Participants were from the community, consumers, providers and AIDS Institute faculty, including Dan Tietz, Dan Belanger, and Clemens Steinbock.</li> <li>- DUH CBI consisted of a blended learning approach with initial and closing in-person sessions, monthly webinars, homework on SAMHSA principles, and individual TA.</li> <li>- Helpful strategies to make people who use drugs feel welcome and safe include assessing first point of contact, creating a Statement of Values, and making bathrooms safer spaces for drug consumption by installing sharps containers.</li> <li>- Branding has been created to identify centers or agencies as safe spaces. There are posters and decals that agencies can put in their front doors.</li> <li>- Mr. Curry advised attendees to consider how they will include people who use drugs in quality.</li> <li>- A report on DUH CBI will be distributed after cohort 2 of the initiative.</li> <li>- Mr. Curry informed the committee about new materials available to order from the AIDS Institute’s education and training unit. <ul style="list-style-type: none"> <li>o “You’re in Charge” is a double-sided postcard with a list of questions to ask your healthcare provider and space to write down appointment information.</li> <li>o “Day-One” is a new publication created with consumer guidance and feedback. The postcard advertises rapid treatment within 3 days or a week and features members of the CAC as models.</li> <li>o “You Can Say YES: Minor’s Consent” are pamphlets announcing the new law allowing minors to consent to HIV testing and treatment.</li> </ul> </li> <li>- Comments from CAC members:</li> </ul>

	<ul style="list-style-type: none"> <li>○ Members asked for more details about how minors will be informed about the new consent law and resources. Mr. Curry recommended distributing them in as many ways as possible. Dr. Gonzalez said they are working with NYCDOH on sexual health education and making sure providers ask the proper questions.</li> <li>○ CAC members noted barriers to detoxification which include insurance limits, type of drugs used, previous rehab admission, and methadone use. Mr. Curry will add this to discussions.</li> <li>○ Mr. Curry said that he will also add Medicaid policy to the planning topics for next round and invite Vocal New York to participate.</li> <li>○ A CAC member noted that methadone isn't detox, it's another drug. Detoxing from methadone takes a long time, at least a year.</li> </ul> <p>- Pictures from World AIDS Day can be used for future publications instead of having to request consent for pictures each time they are needed.</p>
<p><b>Working Lunch and Closing Remarks</b>  <i>Dana Diamond and Leanna Thornton, CAC Co-Chairs</i></p>	<ul style="list-style-type: none"> <li>- A CAC member requested that the next meeting be planned around the United States Conference on AIDS (USCA) on Sept. 8-10<sup>th</sup> and asked if funds will be offered for CAC members to go. <ul style="list-style-type: none"> <li>○ Dan Tietz will speak to Dr. Gonzalez about funding.</li> </ul> </li> <li>- Harlem Hospital asked to hold a memorial for Humberto Cruz.</li> <li>- Jahlove thanked the AI for providing funding to attend the Saving Ourselves Symposium in North Carolina.</li> </ul>