

## HIV Quality of Care Consumer Advisory Committee Meeting

55 Exchange Place, New York, NY

March 14, 2018 9:00AM – 12:30PM

AGENDA ITEM/TOPIC	DISCUSSION/ACTION ITEMS	RECOMMENDATIONS/FOLLOW-UP
<p><b>Welcome, Introductions and Announcements</b> <i>Leanna Thornton, CAC Co-Chair</i></p>	<ul style="list-style-type: none"> <li>– Leanna Thornton, CAC-co-chair, welcomed the group, and committee members introduced themselves. Dana Diamond, CAC co-chair, was attending the HIV Advisory Board meeting and was not present for the CAC meeting.</li> <li>– Ms. Thornton recognized several returning members to the group, as well as two new members.</li> </ul>	
<p><b>QAC Update</b> <i>Dr. Kelly Ramsey, QAC Co-Chair</i></p>	<ul style="list-style-type: none"> <li>– Considering the meeting’s focus on drug user health, Dr. Kelly Ramsey, QAC co-chair, briefly discussed the stigma surrounding sex and drug use in the United States.</li> <li>– Compared to many other countries around the world, the United States views sex and drug use through a very negative lens. Unfortunately, stigma surrounding both topics has led to difficulty implementing relevant quality improvement programs such as drug consumption rooms.</li> <li>– For any substantial progress to be made in the United States, Dr. Ramsey explained that there needs to be a major shift in how political figures, healthcare providers, and the public view sex and drug use.</li> </ul>	
<p><b>CAC Bylaws</b> <i>Leanna Thornton, CAC Co-Chair</i></p>	<ul style="list-style-type: none"> <li>– A copy of the CAC Bylaws was handed out to all attendees. Ms. Thornton asked that everyone review, sign and hand back their copy of the Bylaws by the end of the meeting.</li> <li>– Ms. Thornton briefly reviewed the mission, guiding principles, and membership roles and responsibilities.</li> <li>– The mission of the CAC is to engage people living with HIV (PLWH) in the discussion of quality of care including, but not limited to, performance measurements, quality improvement projects, quality infrastructure requirements, targeted consumer and provider initiatives, and to inform and</li> </ul>	<p>- For any questions or concerns regarding the current CAC/YACAC Bylaws, please contact Dan Tietz at <a href="mailto:Daniel.Tietz@health.ny.gov">Daniel.Tietz@health.ny.gov</a>.</p>

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	<p>educate committee members and their represented groups about current and future quality initiatives of the AIDS Institute HIV Quality of Care Program.</p> <ul style="list-style-type: none"> <li>– The guiding principles of the CAC include, but are not limited to: <ul style="list-style-type: none"> <li>– A collaborative responsibility to provide recommendations to AIDS Institute staff on quality of care issues that affect PLWHA throughout New York State.</li> <li>– To have a representation of PLWH from diverse communities impacted by the AIDS epidemic.</li> <li>– The planning of CAC/YACAC activities must be dynamic, flexible, and open to revision and redirection as new and immediate needs emerge.</li> </ul> </li> <li>– The CAC/YACAC membership roles and responsibilities include, but are not limited to: <ul style="list-style-type: none"> <li>– Members must convene and attend quarterly meetings.</li> <li>– Provide input on the AIDS Institute Quality of Care Program, including, but not limited to, performance measurements, quality improvement projects, quality infrastructure requirements, and targeted consumer and provider initiatives.</li> <li>– Inform and educate PLWHA about current and future quality initiatives of the AIDS Institute’s HIV Quality of Care Program.</li> </ul> </li> <li>– Ms. Thornton informed the group that the CAC has reached membership capacity. Therefore, if any current members are unable to make at least two meetings per year, she requested that they step down so more people can gain membership.</li> <li>– Currently, 16 members represent the 5 boroughs and 3 members represent other regions of NYS.</li> <li>– An attendee asked how CAC meeting attendees know that they are on the committee. Ms. Thornton replied stating that a person’s presence at the quarterly meetings solidifies their membership. In addition, she clarified that there are no term limits for members.</li> <li>– Several members raised the concern that they don’t have enough time to review and ratify the Bylaws by the end of the meeting.</li> <li>– The group came to a consensus that members have time to review the Bylaws after the meeting and email Daniel Tietz with any issues or concerns they may have regarding the current Bylaws.</li> </ul>	

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<p><b>2017 Ending the Epidemic Data Report</b>  <i>Dr. James Tesoriero, AIDS Institute</i></p>	<ul style="list-style-type: none"> <li>– Dr. James Tesoriero, AIDS Institute, presented on the 2017 Ending the Epidemic (ETE) data report. The objective of the presentation was to update attendees on the core and supplemental ETE metrics for 2017.</li> </ul> <p><b>Ending the Epidemic Core Metrics</b></p> <ul style="list-style-type: none"> <li>– The first core metric reported in the ETE blueprint is “incidence” (number of new HIV infections). The goal by the end of 2020 is to reduce the number of new infections to 750. Unlike new diagnoses, which are counted through public health reporting, this is an estimate that is calculated using a statistical method provided by the CDC, which is always changing. NYS is on track to achieve this goal of 750 by the end of 2020.</li> <li>– The second reported ETE core metric is “HIV status aware.” By the end of 2020, the goal is to increase the percentage of people living with HIV who know their serostatus to at least 98%. Like the core metric HIV incidence, the percentage of PLWH who are aware of their status is an estimate, based on a CDC methodology and NYC refinements.</li> <li>– The third reported ETE core metric is “new HIV diagnoses.” By the end of 2020, the goal is to reduce the number of new diagnoses by 55%. New HIV diagnoses in both NYC and the rest of the state have declined for a third consecutive year, reaching an all-time low of 2,769 in 2017.</li> <li>– There has been a decrease in the number of new HIV diagnoses for non-Hispanic black, Hispanic, and non-Hispanic white groups between 2007-2017. However, there has been no improvement in terms of disparities between the groups.</li> <li>– The fourth reported ETE core metric is “linkage to care after diagnosis.” By the end of 2020, the goal is to increase the percentage of newly diagnosed persons linked to HIV medical care within 30 days of diagnosis to at least 90%. This metric has increased by 12 percentage points since 2013 (currently at 81%) and the state is on track to hit the aggressive 2020 target of 90%.</li> <li>– The fifth reported ETE core metric is “time to AIDS.” By the end of 2020, the goal is to reduce the rate at which persons newly diagnosed with HIV progress to AIDS by 50%. The state is on track to hit this target.</li> </ul>	

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	<ul style="list-style-type: none"> <li>– Because the metric “time to AIDS” requires newly diagnosed persons to be tracked 2 years from the date of their diagnosis, the data for this metric has a 2-year lag. We have seen a huge gain in this target for persons diagnosed in 2013 (2015 reporting year), which has been maintained throughout the last two years of data (2014 and 2015 diagnoses and 2016 and 2017 reporting periods).</li> <li>– The sixth reported ETE core metric is “receiving any care.” By the end of 2020, the goal is the increase the percentage of persons living with diagnosed HIV infection (PLWDHI) who receive any care to 90%. 2017 saw the first positive movement in this metric since 2013, as the percentage of PLWDHI receiving any care increased from 80% to 83%.</li> <li>– Although the state fell short of the 2017 target of 86% for the “receiving any care” metric, 2017 provided solid evidence that data-to-care and other interventions are beginning to make a population-level difference.</li> <li>– The seventh reported ETE core metric is “viral-suppression-receiving any care.” By the end of 2020, the goal is to increase the percentage of individuals living with diagnosed HIV infection and receiving any care with suppressed viral load to 95%.</li> <li>– This viral suppression metric looks at suppression among those people who appear to be “in care” in the surveillance system. 2017 saw continued stability in gains made over the past several years, with an 87% viral suppression rate realized among in-care PLWDHI. The 95% goal is a very achievable goal.</li> <li>– The eighth ETE metric is “viral suppression- PLWDHI.” By the end of 2020, the goal is to increase the percentage of individuals living with diagnosed HIV infection with suppressed viral load to 85%. This metric looks at viral suppression among all people diagnosed with HIV in the state at the end of the year.</li> <li>– There was a 2% increase in viral suppression in 2016, to 72%, which was under the target the state set for 2016 (76%).</li> <li>– The ninth the reported ETE metric is “concurrent AIDS diagnosis.” This metric tracks the cohort of people who are diagnosed with AIDS at the same time as their initial HIV diagnosis. By the end of 2020, the goal is to reduce the proportion of persons with a diagnosis of AIDS within 30 days of HIV diagnosis to 15%.</li> <li>– This final core metric has remained around 20% for years, indicating that the state</li> </ul>	

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	<p>needs to do more to make faster progress in reducing late diagnoses. Not only did the state fail to hit its target for 2017 of 17.6%, the percentage of people with a concurrent AIDS diagnosis increased from 18.8% to 19.8%.</p> <p><b>Ending the Epidemic Supplemental metrics</b></p> <ul style="list-style-type: none"> <li>– The first reported supplemental metric reported is the “stigma measure.” By the end of 2020, the goal is to decrease stigma experienced among PLWDHI by at least 25%. This metric is measured based on the results of the Medical Monitoring Project (MMP).</li> <li>– The MMP uses results from a 10-question scale that looks at four dimensions of stigma including personalized stigma, disclosure concerns, negative self-image, and perceived public attitudes about PLWH. More information can be found here: <a href="https://www.cdc.gov/hiv/statistics/systems/mmp/index.html">https://www.cdc.gov/hiv/statistics/systems/mmp/index.html</a>.</li> <li>– The second supplemental metric reported is “viral load suppression-newly diagnosed HIV.” By the end of 2020, the goal is to increase the percentage of persons newly diagnosed who received VLS within 3 months of diagnosis to 75%. This metric has doubled since 2013, improving from 22.7% to 47%.</li> <li>– The third reported supplemental metric is “sustained viral load suppression.” This metric is defined as the percentage of PLWDH who were virally suppressed (&lt;200 copies/mL) on all viral load tests in the previous two years. By the end of 2020, the goal is to increase the percentage of PLWDH with sustained viral load suppression to 75%.</li> <li>– The fourth reported supplemental metric is “newly diagnosed HIV+ persons who inject drugs.” By the end of 2020, the goal is to reduce the percentage of persons newly diagnosed with HIV who indicate a history of injection drug use to 2.8%. In 2017 the state measured 4.2% (110 people) and if the state hits its 2020 target this will be 42 people. However, the current opioid epidemic is a major threat to this goal.</li> <li>– The fifth reported supplemental metric is “HIV related deaths.” By the end of 2020, the goal is to reduce the percentage of deaths due to HIV to zero. This metric is determined by annual medical chart reviews, performed by IPRO,</li> </ul>	

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	<p>conducted on a representative sample of deaths occurring in NYS among PLWDH. Results will produce the proportion of deaths due to HIV/AIDS. For a baseline, IPRO chart reviews began with 2016 deaths.</p> <ul style="list-style-type: none"> <li>– The sixth reported supplemental metric is “PrEP utilization.” This metric is defined as the number of individuals filling at least one prescription for Truvada within the calendar year. By the end of 2020, the goal is to increase the number of individuals filling prescriptions for PrEP to 65,000. In 2017, 24,284 individuals had filled at least one prescription for Truvada within the calendar year.</li> <li>– The seventh reported supplemental metric is “PrEP utilization- Medicaid.” This metric is defined as the number of Medicaid recipients filling at least one prescription for Truvada within the calendar year. By the end of 2020, the goal is to increase the number of Medicaid recipients filling prescriptions for PrEP to 30,000. In 2017, 6,025 Medicaid recipients were reported to have filled at least one prescription for Truvada within the calendar year.</li> <li>– NYS is outperforming the national measure for “PrEP utilization-Medicaid.” However, a lot of work still needs to be done regarding PrEP utilization among people of lower socioeconomic status and underserved communities.</li> </ul>	
<p><b>European Drug User Health Models</b></p> <p><i>Jason Farrell, Correlation – European Harm Reduction Network</i></p>	<ul style="list-style-type: none"> <li>– Jason Farrell, from Correlation - European Harm Reduction Network, presented on Drug Consumption Rooms (DCRs) in the Netherlands as well as the rest of Europe. This organization seeks to improve the quality and access to health and social services for marginalized groups.</li> <li>– DCRs are medically supervised centers where one can safely use drugs. Their aims are to reduce health problems stemming from problematic drug use, improve access to social, therapeutic, educational, and other health services for people who use drugs (PWUD), and to lower the nuisance of public amenity issues associated with drug use in public spaces.</li> <li>– In the Netherlands, drug use is low as compared to the United States, and HIV, HBV, and HCV infection rates are low for people who inject drugs (PWID). However, the MSM population is increasingly at a high risk for HCV, with a special area of concern for those that inject chemsex drugs. Of the 1037 newly registered</li> </ul>	

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	<p>HIV patients in care at treatment centers in the Netherlands, MSM accounted for 68% of newly diagnosed people.</p> <ul style="list-style-type: none"> <li>– The heroin epidemic ended for the Netherlands in 2008, and most heroin users are about 55 years old. There are about 600 of these users utilizing a heroin-assisted treatment center, where they go to a clinic to use prescription heroin and methadone in a controlled setting.</li> <li>– As heroin became a larger problem in the 1970s, Dutch addiction treatment changed from emphasizing abstinence to harm reduction measures. In the 1990s, harm reduction programming gained support from research that viewed addiction as a relapsing disease, and this led to the first DCRs in the Netherlands in 1998.</li> <li>– Between 2012-2018, DCRs transformed into housing facilities and incorporated alcohol consumption rooms. As the overall drug problem in the Netherlands has improved, some DCRs have closed. This approach towards drug use and addiction has been embedded into the general health care and public health policies of the country, and DCRs are more accepted by the general public today.</li> <li>– In the past three decades, DCRs have been spreading around Europe, with the Netherlands and Germany having the most, at 24 DCRs. Behind them are Spain and Switzerland, with 13 sites. In 2013, the Netherlands closed 7 DCRs due to a decline in the number of people utilizing their services.</li> <li>– There are four DCR models. The first, Integrated DCRs, are large centers that allow for all services, from STI testing and providing food to social work and methadone treatments. Specialized, or stand alone, DCRs are geared towards those who need them in a community. This allows them to provide better attention and cater to their users' needs and schedules, but the services available are only for supervised using and for testing. There are no medical support or case management.</li> <li>– Mobile DCRs have limited hours and services, but are able to cover a wide area to provide methadone, first aid, condoms, prevention materials, and a needle exchange program. Lastly, Housing Facility DCRs have social and medical support</li> </ul>	

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	<p>for loneliness, depression, and stress on top of their drug services, but these services are only open to their residents, who must be older than 45.</p> <ul style="list-style-type: none"> <li>– To start a DCR, Mr. Farrell explained the importance of matching its goals to the needs of the drug users, and the significance of keeping the community involved. Dismantling the perceived fears associated with DCRs will help in implementing DCRs for the first time. In fact, in countries where DCRs opened, reports of drug dealing and drug use declined.</li> <li>– Mr. Farrell expressed how a connection with the community is vital to the success of the DCR. The police, health authorities, local government, and volunteers collaborate with DCRs in order to improve the local quality of life, and to keep others aware of the DCR’s activities.</li> <li>– One CAC member asked how DCRs are funded in the Netherlands. Mr. Farrell answered that it is paid for by health insurance. Another member expressed a concern that some people in the United States may try to purposely “shoot up” in order to gain the benefits of a DCR if these rooms were available here. Mr. Farrell said that collaborations with lawmakers and other organizations can help to work against this, and that a similar argument arose with the needle exchange programs, but in the end the benefits of these programs justify their need.</li> </ul>	
<p><b>Drug User Health Capacity-Building Series and Education in NYS</b></p> <p><i>Robert Curry, AIDS Institute</i></p>	<ul style="list-style-type: none"> <li>– Due to time constraints, Mr. Curry was not able to present at this meeting. His presentation will take place at a future CAC meeting.</li> </ul>	



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<p><b>Harm Reduction in Practice in Ithaca, NY</b></p> <p><i>Dr. Justine Waldman and Leslie Fareed, REACH</i></p>	<ul style="list-style-type: none"> <li>– Dr. Justine Waldman, Medical Director of REACH, presented on the scope and work of REACH, a nonprofit medical practice she founded to promote health equity through harm reduction principles.</li> <li>– REACH stands for Respectful Equitable Access to Compassionate Healthcare and serves all people regardless of ability to pay and is specifically geared toward those who typically face stigma in the healthcare setting.</li> <li>– Dr. Waldman was also part of the first New York State AIDS Institute Syringe Exchange Program Health Hub, offering medical care at a syringe exchange in Ithaca. Health Hubs are nursing-intensive and provide stigma-free, low-threshold access to medication-assisted therapy (MAT) and acute care. There is only one provider at the Ithaca Hub who is cleared to provide buprenorphine to 30 people.</li> <li>– REACH was founded based on the Health Hub model, and is nursing-intensive, treating OUD with MAT, and offering primary care, behavioral health, and Hepatitis C treatment. Several providers are contracted to maximize the number of people who can be prescribed buprenorphine.</li> <li>– REACH also has a peer advisory board and program, a staff advisory board, a food pantry and clothing donations, and a once-a-month veterinarian service. REACH also works with the NYS Opioid Overdose Prevention Program and is a Tompkins County Living Wage employer.</li> <li>– Dr. Waldman cited overdose statistics and mentioned that rural areas of New York are seeing increased drug overdose deaths. Between 2010-2015, there was a 45% increase in NYC of overdose deaths and 84% increase in the rest of state.</li> <li>– Opiate Use Disorder (OUD) is a chronic relapsing disorder. Dr. Waldman noted that the medical establishment often punishes people for the chronic and relapsing nature of OUD.</li> <li>– Treating OUD through abstinence increases risk of death because abstinence lowers tolerance. This means that patients must be monitored and warned of the potential consequences of relapse before they attempt to abstain.</li> <li>– A CAC member who identified as a former drug user commented that many people who successfully abstain from using drugs are not chronically relapsing. Dr. Waldman responded that abstinence is not the right step for everyone, and that</li> </ul>	

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	<p>medication-assisted therapy is a safer step in ending drug use. Additionally, abstinence can be safer or more dangerous depending on the substance.</p> <ul style="list-style-type: none"> <li>– Dr. Waldman observed that while OUD is defined as a disorder, no other physical or psychiatric disorder is met with as much social disapproval or stigma.</li> <li>– A consumer commented on how important it is to treat addiction as a mental health disorder.</li> <li>– Jason Farrell, Correlation - European Harm Reduction Network, shared his view that prevention information is not being provided consistently. More information is needed on “reverse tolerance,” in which an individual’s tolerance to a substance is lowered after a period of abstinence, such as a prison sentence. It was recommended that corrections facilities educate people who use drugs about the danger of overdosing when returning to their communities.</li> <li>– Dr. Waldman made a point that no one would choose addiction. Even if first use is a choice, repeated use leads to brain changes that reduce the capacity to stop. Doctors treat the consequences of other choices (ex: cardiac disease, emphysema, diabetes, obesity) without attaching a moral judgement.</li> <li>– Dr. Waldman reminded the group that words matter, and recommended avoiding terms such as: addict, problem, being clean, abuse, and dependence. She recommended using: opioid use disorder, disease, person with OUD, return to use, and being in remission or recovery.</li> <li>– Dr. Waldman stressed the importance of medication-assisted therapy (MAT) in treating OUD. Access to OUD treatment medication is highly regulated, stigmatized, and high threshold. Additionally, methadone is a highly regulated form of MAT and is only available in cities.</li> <li>– REACH serves 22 counties across NYS. 82% of patients are enrolled in Medicaid, 50% of the patient population also receives primary care at REACH. Over 675 patients were seen in one year for MAT.</li> <li>– Dr. Waldman introduced Leslie Fareed, a client at REACH. Ms. Fareed shared her struggles in juggling COPD and diabetes on top of substance use disorder. She described the barriers and discrimination she faced from doctors and treatment programs due to her drug use, despite doing everything she could to “get well,”</li> </ul>	

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	<p>such as using medication-assisted therapy (MAT). She was eventually referred to the REACH program, and said that from then on, “the ride has been phenomenal.”</p>	
<p><b>Working Lunch and Regional Updates</b></p>	<ul style="list-style-type: none"> <li>– Ms. Thornton reminded the group that they had agreed to read the bylaws and vote on them at this time. The bylaws will not go into effect unless 2/3<sup>rd</sup> vote on them. Any requests to change them should be addressed to Daniel Tietz via email.</li> <li>– Ms. Thornton reminded the group that the bylaws haven’t changed since they were previously voted on.</li> <li>– A CAC member suggested that discussing the bylaws be saved for the next meeting in June, so they can be the first item on the agenda. Another CAC member warned against this, saying that the bylaws are already a year old. The reason they are being reviewed a year later is because it keeps getting delayed to the next meeting. If the CAC delays this review for another three months, they will come back at the next meeting and do the same thing again. An individual bylaw can always be changed with consensus.</li> <li>– Another CAC member proposed a friendly amendment to the motion: those who feel comfortable can sign the bylaws now, but those who want to wait, can wait. The motion was carried.</li> <li>– Ms. Thornton stated that she still felt that there were too many presentations and too little time for questions and feedback from the CAC at this meeting.</li> <li>– A CAC member suggested scheduling only two speakers to ensure there is enough time for a group conversation.</li> <li>– It was suggested that AIDS Institute staff prepare an outline of the presentations and hand it out to the members, so they could go through it and write down questions beforehand for the presenters.</li> <li>– Another CAC member recommended that the committee move beyond the data and focus more on brainstorming solutions.</li> <li>– One CAC member said she didn’t feel like she was participating in the afternoon QAC meeting with the providers, to which all CAC members are invited.</li> <li>– Dan Tietz assured the group that their input, questions, and comments is welcome by the QAC.</li> </ul>	

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	<ul style="list-style-type: none"> <li>– Another CAC member asked if the CAC could have another room where they could adjourn and continue their meeting when the providers come for the afternoon QAC meeting.</li> <li>– CAC members discussed the single-day CAC and QAC meeting format, which began last year. Members agreed to try the single-day format for the June and September 2019 meetings, at which point the group can decide if a single-day CAC and QAC meeting is best for the group.</li> </ul>	
<b>Closing Remarks</b>	<ul style="list-style-type: none"> <li>– Ms. Thornton closed the meeting.</li> </ul>	