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SIM CONSUMER ADVISORY BOARD REPORT OF BEHAVIORAL HEALTH EVENT

BURROUGHS COMMUNITY CENTER IN BRIDGEPORT: MAY 19, 2016

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SIM CONSUMER ADVISORY BOARD REPORT OF BEHAVIORAL HEALTH EVENT

EVENT OVERVIEW

On May 19, 2016 – The State Innovation Model Consumer Advisory Board (SIM CAB) organized a Behavioral Health Listening Session. The purpose of the forum was to offer people in recovery from mental health and/or substance use issues a place to discuss and learn about healthcare access, express their health concerns, and encourage them to take action steps together to address identified healthcare concerns. The event took place at Burroughs Community Center in Bridgeport. Over 65 people registered to attend the event.

The goal of the event was to hear from community regarding their experience with healthcare, to have a broad representation of what it's like to be part of the behavioral health system, and to learn about making decisions from a place of being informed by people affected.

People discussed questions addressing challenges they've experienced in receiving care for mental health and addiction needs, and how we can strengthen the access to behavioral health clinicians. Participants included people who use services, people who provide behavioral health services, and interested community members. The event was attended mostly by providers, with some people in recovery in the audience. This event is part of the SIM consumer engagement strategy in collaboration with the Consumer Advisory Board.



The event brought up discussions about health and practice transformation. People talked about the importance of hearing the consumer voice – or taking into account the perspectives of people with lived experience in mental health and/or addiction. People talked about how all planned innovations can lead to positive outcomes. Health equity was defined as offering quality care, engaging people, at a lower cost. Social determinants of health were also discussed. Lack of psychiatrists impacted people's ability to access care when they needed it. There was a fear about how cuts will affect services.

Whole person healthcare was important to people. Audience members stressed that we need to take advantage of this opportunity to treat whole people. People said, "A sick healthcare system is not a healthcare system, and we need integration and parity to improve it."

People talked about how the State Innovation Model Consumer Advisory Board (SIM CAB) can become the voice of consumers, and how people can take command of their healthcare. People wanted to share information

with SIM, DMHAS, and the Governor's Office. They want to stay in touch over time.

Janet Storey from DMHAS spoke, and addressed the questions of integration, access, and care experiences.

Dr. Schafer spoke and shared information from the Southeast Asian Listening Forum. He acknowledged that when you are looking at a whole population, you may miss certain groups. The Southeast Asian community faces specific barriers, related to behavioral health, that are important to note. Policy must be informed by every day experiences, good and bad. The barriers facing Southeast Asians have to do with cultural distrust of the mental health system and under-diagnosis of trauma. Moreover, the costs of care for medical expenses goes up with co-occurring mental health issues, and it is challenging to refer for behavioral health with a connection to care by the primary care provider. Social factors,

such as poverty, language, and health literacy also play a role in Southeast Asians' lack of access to mental healthcare. The SIM grant helps create changes in the healthcare system, and changes by and for people.

Access to care was noted as a problem. It was reported that some clinics have high turn-over rates of psychiatrists, and wait times for appointments are very long. Turnover of providers in behavioral health care affects people's ability to recover. One audience member said that, although she had a serious eating disorder, she was told that sessions with a dietician were not covered as part of her plan because she was not diabetic.



Some people were being told they needed a higher level of care to access services, or told they were not ill enough for the higher level of care when they were ready to get help. Others shared that they were told, "you are too much of a burden – I can't handle you right now." This is demoralizing and impedes people's ability to access care when they most need it, leading to crisis.

Taking care of the whole body, including medical and dental care, is difficult for some. In working with older people, people talked about lack of dental coverage and how this impacts digestion and people's mental health. Medicare is not planning on paying for dental coverage and this is a big problem. For one person, it was a major challenge to make a dentist appointment, since it had been almost 10 years since her last one. One source of support for dental coverage is via Community Health Centers, where they offer a sliding fee scale. Some said they did not prioritize medical care since addressing behavioral health care was taking up so much energy and time in an uncoordinated system.

For others, the distance between doctors and their lack of communication was a challenge to taking care of the entirety of their care needs. A woman in her 30s who is in recovery said that having one location where all services are provided is "like gold to me," but is not often the case. One participant talked about how they wanted their doctors to be a team, that's located nearby, and who talk and know each other. They discussed issues of trust.

Although consumers felt that providers could improve, consumers were also empathetic to their providers' plight. They notice when their doctors are emotionally exhausted and tired, and recognize that it is difficult for them to care for patients sometimes. It was recommended that doctors have supports too, and that the "us" versus "them" label diminish. People understand that it is hard to provide care if you need care.

People are sometimes asked by their doctor about their preferred communication method, but audience members felt that doctors should also be more open with patients about *their* own communication style. One person who used email as a primary communication tool said it took 18 months to learn that her doctor did not use email with patients.

It was noted that providing education to primary care providers about behavioral health would be helpful. Daniela Giordano, of NAMI, recalled stories of people whose medical concerns were viewed skeptically or completely ignored when it became apparent that they were also dealing with behavioral health conditions. Some doctors dismiss medical issues and only look at patients through the lens of behavioral health issues. People were concerned about the bifurcation between substance abuse and mental health, and wanted doctors to have cross-training between the issues. For these reasons, consumers wanted peer support in Emergency Departments.



Reactions to the care delivery and payment reforms presented as part of SIM were positive. People agreed with the urgency to spend healthcare dollars better and move away from the fee-for-service payment model. One person, who advocated for her family members when they sought care, said she is frustrated that the doctor who saw her family members scheduled more and more diagnostic meetings. This made her distrust him and think it was “all about the money.”

People talked about how we should judge “getting better” with behavioral health. Does that mean maintaining functioning or the measuring the number of times they go to the hospital? People identified a need for home health care and staying in the community to improve behavioral health outcomes.

People liked the idea that care delivery system reforms expand care teams to include nutritionists, pharmacists, and community health workers (including peer supports), but had questions about how they would all be kept on the same page. Some members wished the doctors they have *now* were more connected: “It would be nice if my doctors knew each other, at least.”

People wanted more caregiver involvement in care, but only if it’s okay with that person. One participant commented about a lateral transfer of care and how that affect her. The event wrapped up with a discussion about the importance of understanding cultural dynamics.

This listening forum made clear that there are many opportunities to improve care for those with behavioral health needs. There is support for better access to behavioral health and other services like dental care and nutrition, and improving communication among the members of the care team. The care experience can be better by allowing ways to communicate with the doctor through e-mail or text, and making sure doctors and other health care professionals are being supported and educated about behavioral health.

KEY FINDINGS:

- People talked about the importance of hearing the consumer voice – or taking into account the perspectives of people with lived experience with mental health and/or addiction issues.
- Access to care was noted as a problem.
 - It was reported that some clinics have high turn-over rates of psychiatrists, and wait times for appointments are very long
 - Lack of psychiatrists impacted people’s ability to access care when they needed it.
 - Insurance coverage impacted access to care. One audience member said that, although she had a serious eating disorder, she was told that sessions with a dietician were not covered as part of her plan because she was not diabetic.
 - Some people were told they needed a higher level of care to access services, or told they were not ill enough for the higher level of care when they were ready to get help
 - People talked about lack of dental coverage for the elderly
 - The distance between doctors and their lack of communication was a challenge to taking care of the entirety of their care needs.
- People identified a need for home health care and staying in the community to improve behavioral health outcomes.

EVENT DETAILS

WHAT WE LEARNED:

CHALLENGES ABOUT HEALTHCARE:

Address concerns about how being labeled as a mental health patient can prevent people from accessing physical health services.

SIM CAB FEEDBACK:

RECOMMENDATIONS:

1) INFLUENCE SYSTEMS CHANGE:

- a) People were concerned about the bifurcation between substance abuse and mental health, and wanted doctors to have cross-training between the issues.
- b) Providing education to primary care providers about behavioral health would be helpful.

2) PROMOTE PROVIDER-CONSUMER PARTNERSHIPS:

- a) Consumers wanted peer support in Emergency Departments.
- b) Need for patience, improved communications, and listening between doctors, patients, and healthcare providers. One person who used email as a primary communication tool said it took 18 months to learn that her doctor did not use email with patients.
- c) People liked the idea that care delivery system reforms expand care teams to include nutritionists, pharmacists, and community health workers (including peer supports)

3) ENGAGE AND EMPOWER CONSUMERS:

- a) Diminish the “us” versus “them” label between doctors and patients. Doctors need supports too.
- b) Promote the consumer voice – and take into account the perspectives of people with lived experience in mental health and/or addiction in determining their healthcare.
- c) Encourage people with mental health and/or addiction issues to self-advocate.

STORY HIGHLIGHTS FROM EVENT



Vered Brandman (left) and Katy Curtis (right)

Katy felt extreme pressure and pain in her chest one night and was rushed to the hospital with very high blood pressure. She was told it was not a heart attack, but tests showed that she did have hepatitis.

A few days later, while still in the hospital, she was on the phone with a friend describing the incident that sent her to the hospital, and suddenly felt the same chest pain and pressure again. She figured out that the incident was psychiatric in nature and demanded to see a psychiatrist, who then confirmed her self-diagnosis.

She was told the psychiatrist would be back to create a follow up plan with her, but when it came time for discharge the psychiatrist had not shown. She was told that she could only see him if she was in acute distress. She insisted, saying she would not leave until he saw her.

Eventually, Katy was given the psychiatrist's phone number and told to follow up on her own after discharge. After leaving the hospital, she followed up with that psychiatrist and his treatment team.

What would her outcome have been if she did not advocate for herself?

Vered was in and out of ineffective treatment for 12 years prior to getting a diagnosis and appropriate treatment when she was 20 years old. Since then, she has become an advocate for herself and her peers. Since connecting with her Regional Mental Health Board three years ago she has been more aware of the resources available to her for recovery, as well as opportunities for advocacy and community work, than in the first six years of her recovery.

Together with Katy, she is working on a book project to collect insights from their peers who have received services for mental/behavioral health and addiction challenges, recognizing that the best people to identify needed changes in the system and facilitate those changes are those who have utilized those services.

Vered is also spreading awareness of CT's Regional Mental Health Boards: "It's very unique, and very needed, to have a table where we who are using these services can sit with clinicians and others, to identify needs in our communities and together be part of the solution. We are all equals at my Regional Mental Health Board."