

Consumer Advisory Council

Community Engagement & Outreach Committee

Meeting Minutes

Feb 22nd, 2021

Meeting Date	Meeting Time	Location
Feb 22 th , 2021	1:30 – 3:00 p.m.	Zoom Meeting

Participant Name and Attendance

Participant Name and Attendance					
Jeffrey G. Beadle		Christiane Pimentel	X	Adrienne Benjamin	X
Alan Coker		SB Chatterjee	X	Andre L. McGuire	X
Robert Krzys	X	Soneprasith Phrommavanh	X	Daniel C. Ogbonna	
Velandy Manohar		Taylor Edelmann	X	Peggy Lampkin	
Terry Nowakowski	X	Ann R. Smith			
Others Present					
Jenn Searles (Connie)		Dashni Sathasivam (HES)		Leslie Greer (OHS)	
Terry Gerratana (OHS)		Dawn Fuller-Ball (HES)			
Ormand Clarke (OHS)		Laura Morris (OHS)			

Meeting Information is located at: <https://portal.ct.gov/OHS/SIM-Work-Groups/Consumer-Advisory-Board>

	Agenda	Responsible Person(s)
1.	Welcome	Terry Nowakowski
	Call to Order The scheduled meeting of the Consumer Advisory Council (CAC) Community Engagement & Outreach Standing Committee was held on Monday, February 22, 2021 via zoom. The meeting convened at 1:33 p.m. Terry Nowakowski chaired the meeting.	
2.	Public Comment	Terry Nowakowski
	There was no public comment.	
3.	Minutes	Terry Nowakowski
	A motion was made by Velandy Manohar and seconded Alan Coker by to approve the minutes of the Consumer Advisory Council meeting of December 17th, 2021. The motion carried.	
4.	Q&A from Connie:	Jenn Searles, Connie
	<ul style="list-style-type: none"> Jenn Searles, the Executive Director of Connie, the CT Health Information Exchange, provided an overview of a HIE. Connie is an independent not-for-profit set up by state statue. The Office of Health Strategy was tasked with working with the Health Information Technology Advisory Committee to advise and set up Connie. Connie has an Operations Advisory Committee which is comprised of organizations that have signed Connie's data sharing agreement. There are multiple working groups for example, use case working group or the technology working group. It serves as a feedback and mechanism loop. 	

- Jenn Searles provided scenarios of potential use cases for Connie and discussed how their use case working group develops and researches use cases before they are even tested.
- Connie is trusted and neutral. They are not setup to serve any one group to the detriment of any other group. Trusted as a concept relating to Connie which means Connie has oversight and feedback from those partners who have signed-on. They get a voice in the operations of Connie. The board is made up who is a consumer, insurance, finance, and various state agencies and try to represent all constituency.
- Connie has hired CRISP; the organization manages the HIE for Maryland and DC and services for other states. There are currently multiple HIEs in the country.
- Adrienne Benjamin asked: Who is funding Connie, the board of directors? And what services?
- Jenn Searles responded that Connie is the organization that provides the technology and services for the secure transmission of data, they are not providing medical services. Connie is funding through the federal government through September via HITAC. In the future, funding will continue to include federal funding at some level. There will also be funding coming through the provisions of services to state agencies/organization (e.g. Medicaid) and the funding will come through those organizations. They will also look to have revenue sources from dues or fees from health systems and hospitals from participating in Connie.
- Terry Nowakowski asked what is the percentage completion of Connie?
- Jenn answered that they are 75% of setting up Connie. They are at the beginning of getting data sharing capacity. The secure pipes for data transmission have been established and they are testing dummy data with Yale New Haven Health, Hartford Health Care and ProHealth. They are hoping that a smaller practice, knowing that the big systems are in the exchange, will be interested in knowing their patients are discharged etc.
- There are also technical assistance dollars from HITAC for smaller practices to hook up to and connect to Connie are available through September.
- Andre McGuire expressed his concern for exchanging HIV and substance use data.
- Jenn Searles shared that there is a group of sensitive data, 42CFR, usually behavioral health and substance use data inclusive of HIV data. That data will not be exchanged at the start. Another HIE that they are working with in another state are working through a process of affirmative patient consent to share that information. That is going to be blocked and out of Connie.
- Andre McGuire appreciated the response since those who have HIV or use Truvada are in some cases unable get insurance, so they are hesitant to have that information exchanged.
- Jenn Searles said she would note that someone may be getting medication for a use that is different, what does that mean and what are implications.
- SB Chatterjee asked: given that this is the 4th attempt of the HIE in Connecticut and there has been a great deal of money from the feds which runs out 6 months. Given the pandemic, there is a need for the HIE. There is a report by CHF about the priority of health equity in use cases, governance, etc. It has been acknowledged in the state that if we had a functioning HIE, more lives would be saved. The pandemic has shown the sensitivity in that this is not a technology issue, but rather a business model. The annual revenue is 9.5 – 10 million dollars a year. As a CEO of Connie, how do you plan to address the health equity and disparities issues regardless of the codification of REL data?
- Ormand Clarke asked how will those from low-income communities directly benefit from Connie?
- Jenn Searles responded that regarding equity, we can't fix what we can't measure and cannot see. We do not have insight into the race, ethnicity, language data in our health systems. OHS has

convened a REL roadmap and work group to tackle achieving uniform data collection in Connecticut. Also, in this session OHS has proposed legislation requiring hospitals and health systems and anyone connecting to Connie to collect REL and transmit it into Connie. Patient can still decline to answer. They are always able to do that. In the Maryland HIE, they were able to combine REL data with COVID-19 testing data to provide detailed dashboards to the state to provide more information of disparities.

- In terms of serving low-income communities and where impact can be made, Connie is meeting with the Community Health Center Association of CT (CHCACT) is their first foray to understand better what it is that they CHCACT are doing and how they can assist their efforts. CHCACT wants to get their FQHCs connected in order to get informed with alerts to do patient follow ups in cases of hospitalization or other circumstances. We anticipate that would be one way that this would be Beneficial to these communities.
- SB Chatterjee mentioned the previous attempts for REL data, yet in our APCD database the REL data is so low. Not having REL data now becomes a source of disparity. What is the alternative to waiting for REL data?
- Jenn Searles believes that a big part of OHS's vision of where they are headed of REL data. Connie can be one piece of that of gathering that data and providing that data back to providers.
- Andre McGuire mentioned that Ryan-White has REL data. There has been repeated asks for DPH to get a release with the Ryan-White data. Can Ryan-White get a release with the state?
- Jenn Searles asked to follow up with Andre McGuire.
- Terry Nowakowski asked about Unite Us and Aunt Bertha other referral platforms and will there be a link to those closed loop referral platforms?
- Jenn Searles is in support of having a closed loop referral platform connect to Connie. There is a team piloting this in DC may be willing to share this use case and how could this work in CT.
- Sone Phrommavanh asked if Connie has information from other states related to safeguarding the data collected? Have those state systems ever been hacked or breached?
- Jenn responded that she does not have specific knowledge of a breach and would need to get more information on potential hacking. What is certain is that data security and privacy is of greatest importance. The technology partner they are using are High-Trust certified, industry gold standard for privacy and security for data in IT. The Yale security data team have done an assessment and don't have any concerning findings. She Connie will be able to provide patients to make a request to see who has had access to my information.
- Patients will have capabilities to see everyone who has accessed their data
- Patient will be able to opt-out of data sharing except for a few exceptions. In those cases, your provider will continue to fax information and share information in the current channels, but that data will not be shared in the system.
- Adrienne Benjamin asked if West Virginia's HIE has made measurable impact in health outcomes. Jenn Searles said she does not know, but Maryland would be a good example and she can look into data. Also, Maryland is operating under a total cost of care, so everyone wants to work together to share data and motivation in a different way than we might be motivated in Connecticut.
- Ormande Clarke asked for an example for how a low-income person would directly benefit from Connie.
- Jenn Searles mentioned that in the beginning there will not be individual or patient-facing view of Connie. There is a requirement that eventually patients will need to have access to their complete

record. Low-income residents will likely benefit by giving their providers access to patient data at the point of care is when will start to see that benefit. Also, providing data to support public health via registries, then you will start to see the benefit to underserved communities in health care today.

- Ultimately, Connie’s long-term big picture goals include improving health care outcomes, quality of care, and reducing costs. will be having conversations with DPH DSS and others to discuss how to link FQHCs and other providers together.
- Terry Nowakowski mentioned the community care teams associated with the hospital systems across the state to coordinate care for the individuals with the highest ED visits and barriers to SDOH and comorbidities. The community care teams often do not get information from these folks and they are going to different hospitals. There are pros and cons, however for a highly vulnerable and transient population, knowing where they have been and the types of services they have received would be a plus.
- SB Chatterjee mentioned that Senator Anwar is supporting legislation that would establish commission focused on addressing health disparities.
- Taylor Edelmann asked: has there been consideration regarding the LGBTQ population and having a legal name vs. chosen name as SOGI data collection has in the past been a point of contention?
- Jenn Searles stated that she doesn’t have enough information to ask that today, but her team is thinking about how to build their system to allow for multiple rows of data or information. It is on her follow up list to find out.

5.	LGBTQ Debrief	Taylor Edelmann
----	---------------	-----------------

- Dashni Sathasivam shared the link with the CAC members for them to view the LGBTQ virtual event. She shared that the Commission would be in touch with the final analytics on engagement.
- Taylor Edelmann provided an update on the event. He felt it was a success. There were over 130 plus comments and no shortage of questions from the audience. There wasn’t time to answer all questions. Someone contacted him at work to congratulate him on the event and were interested
- Taylor Edelmann would love for there to be a part 2 follow up. The goal is to get some recommendations and how to push them forward. He sits in on the LGBTQ Health and Human Services Network meetings. The question is what to do with all the information that has been generated, so that there is some movement from what was discussed. People are passionate about the subject matter and with the timing of this being on the heels of True Colors closing, this has been particularly important.
- Adrienne Benjamin asked how do we take the big picture and turn it into policy proposals. How do we operationalize this into something concrete that would make a difference?
- Taylor Edelmann agreed that the energy was there, but things won’t change tomorrow. There was a lot of conversation regarding training. could there be a mandate for training, and how can that be weaved into every agency, while also making it meaningful. Maybe this starts with community and health care organizations. And training needs to be certified. It is also about bringing in people as trainers who are knowledgeable etc. and give them a platform to use their voice. In addition to training, focusing in on the LGBTQ Network as they have funds and are conducting a survey for adults. One of the recommendations was to address the need for data on LGBTQ youth to inform program

implementation.

- Terry Nowakowski responded that there is so much more to do around minors and youth homelessness. There isn't an infrastructure in CT. There is no data on the Youth Service Bureau
- In MN they have an app for Youth experiencing homelessness (YSNMN.org). These are things we can talk about and linking DCF and CSSD and if we could get the conversation going across these sectors. We need data to have a common language. So, if this network does this survey,
- Taylor Edelmann asked: how do we connect the dots? Is a way to create a coalition that is incentivized. People and agencies are supposed to be at the Network meetings, but there are no repercussions if people don't attend the Network's meetings, so what are the mechanisms for accountability?
- Accountability was another underlying theme of the panel. Accountability for training or with workers etc. Just because there are non-discrimination policies doesn't mean that discrimination doesn't happen. Just because training happens also doesn't necessarily guarantee change. For example, this was discussed in the contexted shelters. Maybe this could be narrowed down for coalitions segmented by medical, behavioral and housing focus.
- Adrienne Benjamin asked maybe there should be a homeless shelter specifically for LGBTQ youth. In standard homeless shelters, LGBTQ youth may not feel comfortable. Could there be a request for a program or LGBTQ shelter? From her perspective in social work, treating a lot trans teens, the first person they might come out to their pediatrician, if that pediatrician seems affirming. Potentially focusing training on the pediatricians might be helpful to narrow this down and provide a place to start. In her social work program, they mandated requiring one continuing education unit for cultural competence and one unit for veterans every 2 years. Is this something that was/can be done through state legislation or through the Social Worker's Association.
- Terry Gerratana shared the legislature by and large have not been that amenable to mandating specific training approaches for specific professions. It is usually general requirements through the profession or trade and then for continuing education and is based on accredited entity. She liked the idea of targeting pediatrician and something that has meaning and substance.
- Taylor Edelmann mentioned that a significant number of providers are prescribing blockers. If we have training mandated, who will provide the training? Is there a list of vendors and how do they prove their competency?
- Terry Nowakowski mentioned that the faith-based community would be another group that could benefit given the historic tensions in the faith-based community. If there is desire to bring the conversation to a larger group of people, then it would make sense to bring these community providers into the discussion.
- Taylor Edelmann mentioned that outreaching with faith-based communities historically have been challenging. There are some affirming churches, but there are many other churches where that is not the case. The biggest challenge is to get buy-in with church leaders and figuring out how to determine that message in a sensitive and authentic way.
- Terry Nowakowski stated that many faith-based churches are being funded by the state like DSS or DMHAS and could elevate the conversation to what are the rights of human being. If they are being supported by tax dollars. She acknowledged that this would be provocative.

	<ul style="list-style-type: none"> • Terry Nowakowski is having their March forum featuring DCF and their Families First initiative. This is the right time because they are just building their infrastructure out through a prevention model and could launch some kind of discussion and link it to the work being done at the Partnership. They have 5 million dollars from HUD to end youth homelessness and data that needs to be collected. There are some intersection points. • Dashni Sathasivam also shared the Kate McEvoy attended the event and placed her email in the chat. • Taylor Edelmann lifted up that informed consent and gatekeeping were raised and a potential step could be collecting patient stories, potentially from panelists and the community. • Adrienne Benjamin added that as far as churches, why not start with those we know are affirming and accepting attitude, building a coalition and have those churches, from a spiritual sense raise awareness among other churches. 	
7.	New Business/Announcements	Terry Nowakowski
	<ul style="list-style-type: none"> • There were no new business or announcements discussed. 	
8.	Adjournment	
	Terry Nowakowski adjourned the meeting at 3:07 PM.	

DRAFT