

**Consumer Advisory Council**

**Consumer Engagement and Outreach Standing Committee**

**Meeting Minutes**

**September 21<sup>st</sup>, 2021**

Meeting Date	Meeting Time	Location
September 21 <sup>st</sup> , 2021	3:00 – 4:00 p.m.	Zoom Meeting

**Participant Name and Attendance**

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Adrienne Benjamin	X	SB Chatterjee	X	Soneprasith Phrommavanh	
Taylor Edelmann	X	Marlyn Coriano	X	Ann Smith	X
Terry Nowakowski	X	Peggy Lampkin	X		
Velandy Manohar		Daniel C. Ogbonna			
Others Present					
Ormand Clarke (OHS)		Leslie Greer (OHS)			

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

	Agenda	Responsible Person(s)
1.	<b>Welcome</b>	<b>Taylor Edelmann</b>
	Call to Order. The scheduled meeting of the Consumer Advisory Council (CAC) Community Engagement & Outreach Standing Committee was held on Tuesday, September 21, 2021, via zoom. The meeting convened at 3:04 p.m. Taylor Edelmann chaired the meeting.	
2.	<b>Public Comment</b>	<b>Taylor Edelmann</b>
	<ul style="list-style-type: none"> <li>There was no public comment.</li> </ul>	
3.	<b>Approval of August 24th, 2021 Meeting Summary</b>	<b>Taylor Edelmann</b>
	<ul style="list-style-type: none"> <li>A correction was noted by SB Chatterjee on page seven. The minutes should read DDS instead of TMR. On page nine, instead of real data it should be REL data.</li> <li>Taylor Edelmann made a motion to move the August 24, 2021, minutes. <b>Motion Passed.</b></li> </ul>	
4.	<b>CONNIE, Opt -out and roll out date</b>	<b>SB Chatterjee</b>
	<ul style="list-style-type: none"> <li>SB Chatterjee provided an update on CONNIE – opt in and opt out. SB forwarded the group a copy of his six-page public comment sent to OHS on the Five-Year Statewide Health Information Technology Plan. Meaningful consent is basically getting permission from the patient not just in terms of treatment but also in the terms of the use of the data. Some states have an opt in where you ask the consumer to ask the patient, whether they want their healthcare data to be a part of the HIV, PCT or whatever identifiable data.</li> <li>CT is an opt out state which means the data is available unless informed the data is unavailable.</li> <li>CONNIE is currently working on a consent mechanism for completion in 2022.</li> <li>Reference made to presentation of the CT Data Collaborative done by OHS specifies you ask the patient/consumer because you cannot force them to divulge data. There is a lot of sensitivity around this issue. The Bill was passed encouraging agencies to collect this data which took three years.</li> </ul>	

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<ul style="list-style-type: none"> <li>• There is medical data which is opt out that we have already consented for them to use medical data within certain constraints. This data is an opt in and the medical data is an opt out. Need to work together to do both if we are going to ask for consent.</li> <li>• REL data will be used by the physicians to precisely know the race, ethnicity, languages etc. for analytics and for physician practices.</li> <li>• Discussed Cedar Bridge has a certain timeframe to develop a tool to determine health standards and the health equity dashboard which will be approximately in another two years.</li> <li>• There are still a lot of questions of trust. How can we ensure trust? We need a meaningful conceptual framework, and we need a system to back it up, like the consent.</li> <li>• Reference made to a book on ethics and consensus and erosion of medical consent and how consent and data are eroding medicine, because of technology and practices. Also, reference made to a paper written by a Harvard Law Professor about informed consent and medical artificial intelligence.</li> <li>• The Consumer Advisory Council was mentioned in the Health Care Cabinet meeting today while discussing core data. Planning to have an education outreach to the consumer about the data opt in, opt out, or whatever the council can hammer out from a policy perspective. As a consumer, we can have a far better outreach or hands on in the communities, which would be a position for the CAC to investigate. In terms of education outreach, we can hold town hall meetings and distribute literature.</li> <li>• Patient portals and access to it, mobile apps etc. are on the state agenda but not quite prepared for it because we still must educate our consumers from our perspective as a consumer and get them access. From a Consumer Advisory Council perspective, how do we put together an outreach education program, or digital health program?</li> <li>• Chapter one in health literacy would be digital health opt in or opt out REL data. What does it mean to access a patient portal or mobile apps for instance. How would we do outreach and open for a syllabus?</li> <li>• Adrienne Benjamin pointed out last year in New Britain and probably Hartford, Bridgeport, Waterbury and New Haven had significant amounts of families without Wi-Fi. The inequity in electronic availability is so predominant.</li> <li>• Terry Nowakowski posed the question, where do we do you think we can be most useful to help those most vulnerable? Perhaps a roundtable discussion and have it recorded on Facebook to get some community input.</li> <li>• We do not want to tread on organizations that are already addressing some of these issue denominators. Health Equity Solutions are part of the Connecticut Foundation on leadership of associated health. We do not want to reinvent the wheel. We can also be a broker, so to speak, so we can use our voice to carry the message across the state or across another body, so we can be like a hub.</li> <li>• Brief discussion on digital health equity. Will add it to the next agenda for further discussion.</li> <li>• Terry Nowakowski discussed a meeting she attended with Vicki Veltri and Kim Martone of OHS. It was asked if the Consumer Advisory Council would consider going out into the Community to talk about CONNIE and the opt in or opt out to get some reactions from folks. We can have it as part of a larger discussion. We can consider discussing the two elements and getting some folks voices into the discussion that we can memorialize in certain communities.</li> </ul>
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<p><b>Updates on Autism Concerns</b></p>	<p><b>Adrienne Benjamin</b></p>
<ul style="list-style-type: none"> <li>• Adrienne Benjamin provided an update on autism concerns. Reported autism is pretty complicated these days depending on who you talk to. There are a lot of people who are very high functioning, but that really does not reflect the vast majority of people with autism, maybe that's two or 3% but they have a big voice. There's a little bit of a distortion field and in the work of how to move forward with resources for people with autism, because the highest functioning most capable people talk about autism is a gift and it's actually listed as a disability in the DSM and it's a spectrum. It's become more confusing talking out in the world about the needs of people with autism.</li> <li>• In Connecticut to make it more confusing resources for people with autism are divided into two camps, if someone with autism diagnosed with autism has an IQ over 70 they are eligible to get on the waiting list for a</li> </ul>	

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waiver from DSS. These are pretty great services, but the waiting list is pretty much like 10 years.

- The other part of the autistic population in Connecticut is people whose IQ is under 70 and they are eligible for services through the Department of Developmental Services, which used to be the EMR and now it's DDS, but for the most part, children with autism get services through schools. There are mandated services through the schools, they're not perfect and parents have to fight hard to get what they need for their kids, but there are services to the schools till 21.
- At the age of 22 there is something called the cliff, which is once school is over, there are no mandated services for anyone with autism or intellectual disability period.
- In Connecticut we have the Department of Developmental Services which does offer things but it's scarce.
- Adrienne Benjamin is a member of The National Council on Severe Autism, which is a national online advocacy group and Autism Speaks, which has had a 16- or 17-year history and is very active around the country.
- The current data on autism depending on who you believe it's about one out of 54 kids one out of 65. California and New Jersey have good data.
- After kids graduate from school, what do they do? Adrienne Benjamin informed the group her daughter has intellectual disability and autism. She was eligible for the Department of Developmental Services funding and can go to a date program in Hartford called Harc. Her daughter is physically a small person. Some parents with larger sized boys in their twenties were not able to attend. The program did not have the resources to manage these large kids that needed a one on one and were turned away. There is a huge need but the funding it takes to have one on ones is expensive.
- There is a Fair Labor Law called 14C that allows people to hire someone and pay them sub minimum wage. Some of the disability rights activists are not in agreement and are trying to get rid of the law that protects the more disabled people who otherwise wouldn't be able to go anywhere and get a job.
- There's a move to get Medicaid to pay for an intentional community of people with autism who want to be with other people with autism.
- Discussed having a forum with different perspectives to talk about these issues. Need to try to figure out how to make services that fulfill the needs of the whole spectrum. Right now, the focus is on only on one end of the spectrum and not the whole spectrum. Perhaps have someone from Autism Speaks, or come up with some ideas on who we could bring in to discuss issues, including moms and people with autism to talk about their lived experience.
- Need to figure out how to get this looked at in a way that's not hostile. Online there is a lot of hostility between some of the groups.
- SB Chaterjee commented we need to get data and also talk to people and get into the causation thinking part of the problem. Perhaps talking with Legislators?
- Pediatricians might be a way to go, because most Pediatricians will identify a child somewhere between 18 months with severe autism and they'll get funneled into the birth to three system. They are then eligible for more special needs help in the school system before they can start kindergarten.

<b>6.</b>	<b>Survey Results, Updates LGBTQ task force</b>	<b>Taylor Edelmann</b>
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	<ul style="list-style-type: none"> <li>• Taylor Edelmann shared the survey results from the CAC prioritization survey. There were eight topic areas that were defined. One is the highest priority and nine is not very high priority, the lowest priority. There were four that stood out.</li> <li>• There was an overwhelming vote for Maternal Health among Bipoc Communities, which is black indigenous people of color communities. In second place with 75% of the votes was autism. Since there was a tie with group homes for sixth place, we can include some elements within the discussion. Number three was health equity boys</li> </ul>	
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	<p>and men of color. LGBTQ was number four. We might be able to take this out due to the Ad Hoc committee being formed.</p> <ul style="list-style-type: none"> <li>• These survey results only reflect 12 submissions which does not represent the entire CAC.</li> <li>• We had a tie for sixth place for 1st Generation Immigrants and Long-Term Care for immigrant groups. Perhaps we can include one another, since they seem to go together</li> <li>• There were only 12 responses for the Ad Hoc Committee for LGBTQ. Five members volunteered, but only one person entered their name.</li> <li>• We will send a blast email and hopefully get more persons to respond.</li> </ul>	
7.	<p><b>Updates on the Bench mark data on Health Care costs [as it affects Health Equity, Accessibility and Affordability]</b></p>	<p><b>Terry Nowakowski</b></p>
	<ul style="list-style-type: none"> <li>• Terry Nowakowski suggested to form small group to put together a project plan. What are some of the ideas? Where can we start?</li> <li>• Would like to get out in the community to hear what they are experiencing and draft a report from the Consumer Advisory Council.</li> <li>• Anyone on today’s call willing to serve on the Ad Hoc Committee, please contact Terry Nowakowski. Terry offered to have the informal meeting at her house or Winding Trails. Ormand Clarke will check to make sure it is okay to have a non-formal meeting and not record it. The meeting will be September 29<sup>th</sup> @ 10:00 a.m.</li> <li>• Will provide an overview from the informal meeting at the next CAC meeting to discuss with the council.</li> <li>• Next meeting will be Tuesday, October 19, 2021, 3 -4 pm. and the next CAC meeting will be October 12, 2021, 3 – 5 pm</li> </ul>	
8.	<p><b>Adjourn</b></p>	<p><b>Taylor Edelmann</b></p>

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