

Consumer Advisory Council
Consumer Engagement and Outreach Standing Committee
Meeting Minutes
August 24th, 2021

Meeting Date	Meeting Time	Location
August 24th, 2021	3:00 – 4:00 p.m.	Zoom Meeting

Participant Name and Attendance

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Terry Nowakowski	X	Velandy Manohar	X	Daniel C. Ogbonna	
Adrienne Benjamin	X	Soneprasith Phrommavanh	X	Peggy Lampkin	
Christiane Pimentel	X	Marlyn Coriano	X	Andre L. McGuire	
SB Chatterjee	X	Ann R. Smith			
Taylor Edelmann	X	Michele Scott			
Others Present					
Ormand Clarke (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 August 24 th via zoom. The meeting convened at 3:05 p.m. Velandy Manohar chaired the meeting.	
2.	Public Comment	Velandy Manohar
	No public comment was raised	
3.	Approval of the June 4th Meeting Summary	Velandy Manohar
	A motion was made by Adrienne Benjamin and seconded by Velandy Manohar to approve the minutes of the Consumer Advisory Council. The motion carried.	
4.	Proceeding according to the agenda	Velandy Manohar
	<ul style="list-style-type: none"> • Velandy Manohar noted that the June 4 meeting’s minutes were distributed; however, they were a bit late. He said that several important/critical matters were recorded in the minutes, including the points Terry made about what the group should prioritize for discussion • Velandy Manohar suggested the formation of an ad hoc committee to review the recommendations of the LGBTQ report. He stated that he had already sent out his comments on it, and there are a lot of good substance entailed. <p>He referenced the seven points that Terry Gerratana made:</p> <ol style="list-style-type: none"> 1. First generation immigrants and challenges and barriers experienced. 2. Long term care, especially for immigrant groups: very often there is no one who looks or speaks like them in these settings. 3. Ethnic, racial and cultural differences 4. Executive order #5: Cost Growth Benchmark and Primary Care Initiative 5. 4. Other OHS initiatives as they come along CE & O to organize some listening sessions 6. 5. Health Equity and Boys of Men of Color 	

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7. 6. Group homes

8. 7. Maternal health among BIPOC

- Velandy Manohar mentioned that residents in corrections services, as a group is another issue. He explained that correctional officers and correctional residents/inmates do not receive proper care for a number of reasons, including ethnic and racial, and this is a very important.
- Velandy Manohar stated that as it relates to order 5, cost growth benchmark and primary care initiative, there is need to explore how to go forward on along other OHS initiatives as they come along.
- Velandy Manohar commented on issues of the lifespan of men of color, health equity, boys and men of color, group homes, maternal and baby survival, and the bipolar communities. He mentioned that a few years ago, in 2018, maternal and infant mortality rates were worse than the period the civil war.
- Velandy Manohar spoke of the great progress on specific effort, including the February 10, LGBTQ event. He conceded that there are several important matters, all equally important, that can be addressed with the aid of expert assistance.
- Terry Nowakowski recalled that Adrienne had earlier referenced the Autistic community as well, and thought it would be a good idea to make that one of the focus areas, as well.
- Adrienne responded, indicating her agreement, suggesting that she would like to have a discussion on how the CAC will address Autism, stressing that there are several unmet needs among the population.
- Velandy Manohar said it would also be good to make this a topic of discussion, as well.
- Adrienne stated that some of the needs are more related to housing and residential options. Some of them are providers who understand autism, which is a major issue, adding, "That's a huge issue, and especially needy are those who are on the more severe end of the spectrum."
- Adrienne stated that individuals who are at the higher functioning level have some measure of capability to self advocate and speak for themselves, which is about a third of the autistic population. And, even so, they are not having all their needs, met.
- Adrienne stressed that those existing at the severe end of the spectrum experience combined intellectual disability, possibly epilepsy, and comorbid issues stressors is a real critical issue. She mentioned that some kind of broad based discussion with many different points of view and invite the families of those folks to discuss their experiences. She said she did not have a defined program as yet but would like to open a discussion on the topic.
- Velandy Manohar suggested that Adrienne write out the first seven or eight points that Terry gave indicating his preference to review written information.
- Velandy Manohar recommended adding these five points away, including the developmentally disabled individuals. Adrienne recommended that the next subject should be held at the level or scope of the recently held LGBT community at which the CAC would invite a wide public audience to present and discuss. He also suggested that the needs or experiences of the affected family members should be considered. He requested that the list should be ready to be integrated in the next meeting's minutes. Adrienne agreed to do so. Adrienne expressed appreciation for the intention to focus on the health issue.

Velandy Manohar concluded his discussions on matters arising from the minutes and thanked the group for participation in the discussions.

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5.	LGBTQ report's next steps.	Taylor Edelmann
	<ul style="list-style-type: none"> • Taylor stated his report will be abbreviated in order to accommodate other members' views. He followed up on the conversation about creating an ad hoc committee and trying to dedicate a little space for planning our next steps. He stated that the next step is not yet determined/decided on and if there were others of the group who were interested in contributing, they may. • Taylor stated there are several personal issues that we may discuss including providers and licensure and training, or are we going to go a different direction by discussing housing. He stated he was of the view that several of us were in agreement that, maybe, there could be a focus on providers, recalling that Terry had mentioned that there were mentions of, for example, DSS. He expressed that he was open to following any direction that the group ventured. He said he would like to see the group move forward and certainly get something more concrete, since there was a lot of energy, time and effort, in prior discussions. He recalled that Dashni had compiled the report for the CAC. • Taylor stated that prior to Dashni's departure, he worked with her in trying to create some kind of community facing infographic to get the main point across; however, he was unsure of the level of her success as she was involved in several other activities, and, likely became overwhelmed. He offered to send Dashni an email to ascertain whether there is an existing draft or valuable information that she would be willing to pass along to the Outreach workgroup. He stated he and Dashni's successor would review it. • Taylor conceded that that was something in the preliminary stage and did not materialize much, due to the brevity of time. Taylor conceded that summer is challenging period of the year and with people on vacation, folks involved in other competing activities, important matters evade important focus. This is a transitional period, anyway, he noted. He acknowledged that the main reason for including the topic on the agenda is to hold space for them to figure out how the CAC moves forward to create ad hoc committee and he was confident that there would be general agreement. • Velandy Manohar stated he had provided his own annotated comments (6 pages, he explained) on the report and it should be available and easy to follow. • Taylor acknowledged that Dr. Manohar's comments, as always, are very thorough, so he appreciate that immensely. • Velandy Manohar mentioned that there is an overlap with Adrienne's interest. He recalled that Terry had verbalized an interest in discussing housing. • Terry inquired from Taylor whether, according to the LGBTQ report he was suggesting that persons interested in that committee create a little project plan together on some of the things he thought could be accomplished in a year. • Taylor responded in the affirmative, explaining that he was thinking of making it simple by everybody providing their ideas. He said that he believed a one year timeline would be adequate, but if required, the timeline could be extended for an additional six months. After this period we will have an assessment/evaluation of progress, however there is need to start somewhere. 	
5.	Planning for Next Event	Velandy Manohar
	<ul style="list-style-type: none"> • Taylor stated it was necessary to create an outline and some actionable items and then, figure out who do we need to contact to make this happen. • Terry asked, "With all this information, where do we go from here?" • Velandy Manohar enquired of Terry, whether it were possible to acquire funding for somebody like Miss Everett somebody to lead the meeting because there is need to have someone with expertise some of us need expertise to set this up. 	

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- Terry responded that she was not sure about funding and doubts there is a contractor. She asked Ormand if he had knowledge of a contractor being secured.
- Ormand responded that it was not to his knowledge that a contractor secured. He added that he was doing his best to assist for now but was not sure whether or when there would be an official replacement for Dashni.
- Adrienne stated that she was, and that, there is need for official administrative help.
- Terry admitted that it has been quite challenging the last few weeks with a lot of situations brewing, and so the CAC lack the administrative support. She acknowledged Ormand's help and thought she had sent out invitations for this meeting, earlier. She mentioned that there was a bit of confusion with her sending out invitations via Teams while another was sent out by Zoom. This underscores the need for administrative support, so this is affecting the process especially that members of the group all involved in several other competing commitments.
- Terry suggested that the group try to synthesize that list, which she reviewed prior to today's meeting that was just approved and there are so many.
- Terry suggested sending out a survey to get people's input on how they would like to prioritize for this year, there would be some way to do that, I think we could make this a little bit more analytical. She said that she recognize that the LGBTQ event was major success and is thinking that there is real interest in the area right now.
- Velandy Manohar was in the affirmative (he said, "Right!").
- Terry said she was interested in hearing from the new members that are in attendance to the current meeting/call or that are part of the consumer Advisory Council. For example, what are their priorities? What were their abilities or areas of strengths?
- Terry mentioned that pastor McGuire stated he would have attended today's meeting but he was not present. She recalled that one of the issues they spoke about approximately one year ago, and would very comfortable doing, is a focus group with African American males in his community that participate in his church. This would help to develop a better understanding of their primary care needs which, as known, represents a major in the healthcare system. Terry added that those are matters which are within her thoughts in terms of where to prioritize. She acknowledged that Adrienne could probably connect the group to a community of person living with and or involved with autism. Terry also said that Taylor's interests/initiatives was an important issue as well.
- Terry said, trying to determine/conclude how the CAC progresses without administrative support is important; however, first and foremost, how prioritization on what's important to the larger group.
- Velandy Manohar stated we need to hear from the new people on areas of prioritization.
- Terry was in agreement.
- Adrienne stated that this could be mentioned in the general meeting, as she supposed the new members were not in attendance, today. Terry agreed but noted that SP of the general group along with Marilyn, a new member was in attendance. Terry confirmed that Christiana was present; however her video was not working. Terry sought the group's thoughts on prioritization of focus areas.
- Taylor stated he thought the survey ideas easy enough and that he could assist with that, for example initiating a survey monkey or even a Google forum.
- Terry supported the idea.
- Christiane stated that she was very happy to hear that the group is trying to do outreach and believes that in order to accomplish what we want to do with this Council, we have to do a lot of outreach to

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access the target population so very happy to hear that and, of course, being an outreach coordinator, she supports outreach.

- Velandy Manohar expressed to Christiane that her expertise is very much needed.
- Terry agreed.
- Terry expressed/proposed that for some of the groups that we may like to make connections with Christiane, since her expertise could help us to establish connections.
- Christiane requested Terry to clarify what she meant.
- Terry stated that issues such as challenges experienced by the LGBTQ community, folks that have autism and families that experience autism, maternal child health, and primary care as it affects inner-city dwelling African American males example, are major issues in our local communities and the country in general. She explained that there's a list of different things that we could focus on and queried whether it would be feasible perhaps host an event that could be live streamed from one of her clinics.
- Adrienne stated that that would be interesting.
- Christiane responded that perhaps, she could. She also said that she had gotten good with her role and that she could find events that are already happening and coordinate with the event organizers. She gave as an example, coordinating Father walked with me.
- Pimentel stated that tabling is always a great opportunity, but always finding a way to partner with somebody who's already doing it is also a good. She explained, "We don't want to double up on what somebody is doing, and if somebody is an expert at something it's better to connect with them instead of trying to reinvent the wheel."
- Terry responded, "Correct absolutely."
- Velandy Manohar stated that looking at the success of the February 10 meeting, we got help from varied sources by coordinating with others who were of the same interest.
- Adrienne: If we could all meet in person, because I feel like I know so little about the new folks and I know we've got coven.
- Adrienne suggested that for those vaccinated with masks on maybe for group could meet somewhere and just spend a little time getting to know each other what each other's expertise areas of concerns.
- Adrienne stated that we can have Zoom meetings of course, but inquired off the possibility of meeting and spending some time on a Saturday like three hours together.
- Velandy Manohar stated that he was fully vaccinated and that Adrienne's suggestion about meeting in person one day of the week, could be part of the survey. Velandy Manohar thought three hours in a closed room was inadvisable and propose an open space.
- Adrienne: "Okay big room."
- Terry inquired from Ormand, on hearing various suggestions for in person meets, whether there were any OHS rules/stipulations related to meeting in person. Ormand responded that he was not aware of any specific stipulations in terms of hosting community meetings in person.
- Terry supported the idea of meeting in person but that she was aware that people would be traveling from distant locations to attend.
- Terry stated that she supported the idea of a central place that will be feasible to all would be preferred and supported Adrienne's recommendation for an hour and a half.
- Velandy Manohar recommended a hybrid meeting since some people are driving too far, maybe better off with hybrid.

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- SB Chatterjee stated that needs a chalkboard meeting where, for example, where and when he starts his agenda items they could/would be understood.
- SB Chatterjee expressed that he was unable to upload for sharing with the group. He stated that he would proceed without sharing the files. He mentioned having completed work related the public health, notably in the realm of social determinants of health and there is a formal program that DPH underground it's been about a year now and it is finally coming to a close, in fact, the launch meeting is on August 26 at 10:30 AM. He stated entailed five year planning. This is a very involved meeting and was focused on Hartford, he noted, and which allowed folks at the Hartford Town Hall. He stated that the meeting or initiative uncovered/ revealed/provided insights on the impact of economics economic policies, and so on, as a social determinants of health.
- SB Chatterjee stated that there were some technical glitches in sending out a six page testimonial and will resend that out via email later. He stated that he thought it would have been posted online but it's not yet. He stated that it is fairly comprehensive and tied with what we are doing at OHS and specifically with issues as race and ethnicity, language data, legislative bills that were passed recently. He stated that there is increasing appreciation focus on data use and there's a lot happening from policies and consent policies. He mentioned that various research has been done on Rhode Island Massachusetts as they have different consent policy than Connecticut.
- SB Chatterjee explained that all our healthcare data in Connecticut is frequently recognized as opt in while Massachusetts uses opt out. At Dr. Manohar's request, SB Chatterjee explained the difference between the two. He stated that basically in Connecticut all our healthcare data by default is referred to as opt out further explaining that whosoever is authorized to look at it may look at it and if one wishes to opt out of that default setting that is called opt out. In other states, is in the reverse. In Massachusetts one can look at one's data unless one specifically indicate or designate an institution to look at it. There are deep policy indications for that, he noted. The reason that it is important is in context of the way the data is being used. He stressed that healthcare data has a special meaning for a variety of reasons, one is that it is getting very granular and very precise and accurate like genomic data. He stated that one's genomic data also includes one's family's data because families are genetically and so there are several policy indications for this.
- SB Chatterjee stated that from a consumer's perspective we are required to concentrate on two areas. One is an education program about consent policies and also important informed consent because now this data is being used because it is complementing the work of physicians.
- Velandy Manohar expressed the importance of protecting patients' personal data and that failure to protect genomic data people would be able to monetize all the health genomic information. He stated that there must be a reason that the state has this option.
- SB Chatterjee stated that major strides have been made in relation to topics of race and ethnicity however we should not lose focus because there remains a big gap which needs to be filled. He stated that he's open to further discussion on this topic and resend out an email again. Both he and Velandy Manohar expressed the need to secure health information data. SB Chatterjee, for instance, noted how the absence of real data during the pandemic affected healthcare in the state.
- Velandy Manohar next invited Adrienne to speak on the issue of autism. She stated that the rate of autism has been skyrocketing for the last several years it's now approximately one out of 54 children. She continued, indicating that the American Academy of pediatrics in 2019 stated that they thought around 40% of people with autism also have intellectual disability, meaning they have an IQ under 70, therefore, she was guessing that data come from eight year olds because that's usually, when eight

year old eight year olds was like the formal time when that is identified. So if the rate is now 2% and 40% of that 2% have not only autism but intellectual disability, we have a lot of challenges ahead and we already have the challenges ahead. She said whenever autism started spiking- approximately 15-20 years ago, those kids are now young adults and housing is unavailable. She noted that already housing is expensive in Connecticut and affects those with individual does diagnose with the disease and require independent housing, explaining that there are very capable people with autism, as well as the folks that have many more challenges and specific needs.

- Adrienne mentioned that the DSM-5 (diagnostic and statistical manual) identifies three levels of autism- Level 1: requiring support; Level 2: requiring substantial support; and level 3: requiring very substantial support.
- Velandy Manohar stated that this is an important subject.
- Adrienne stated that the people with more severe autism are typically invisible in society because they're too challenging to bring out into the Community and aren't able to sit in public places as restaurants stably/composed and neither in swimming pools. They really have their special needs.
- Adrienne explained that some members of this community are disruptive and possibly acting out non-verbally, becoming very frustrated easily. They are rarely seen by/in the general public. She stated that persons at level 1 appear at the legislature and express their needs as well as appear on TV, which is great. She referenced a neurosurgeon who's autistic. Yet, there is an unfortunate gap in needs and available services.
- Adrienne stated that in terms of visibility and people's understanding, when we go to the legislature and say we need a lot more resources for people with autism they're seeing people that can live on their own.
- Adrienne stated many people don't want to be identified with the severe autistic people and she has dealt with this, because of her 25 yr. old daughter who has lived experiences with this diagnosis. She expressed desire to figure out a way to address the needs of the whole spectrum and to identify and address the needs of the whole spectrum.
- Adrienne stated that she was not sure what other people knew about this topic and would be interested in what those listening think about if they know much about it, or if they have given it any thought.
- SB Chatterjee questioned how much studies are there in Connecticut regarding autism. He acknowledged that there is insignificant focus on this health issue.
- Adrienne stated that's an interesting question; however, she was not sure about studies, but the way services are organized in Connecticut is two tiered. So, somebody that has autism, but is has a high IQ an IQ over 70 don't get services from the developmental they get services from DSS (department of social services). She stated that frankly, DSS offer great services, but the waiting list is horrendous. As a result, young teenagers and little kids who really do need major are placed on extensive waiting list. She noted that individuals dually diagnosed with intellectual disability and Autism receive their services through the DDS (department of developmental services).
- Adrienne stated that it's well over a couple of years that she has requested of the Commissioner of DDS (whom she acknowledged to be "a lovely person, very hard working" for data on what percentage of the 16,000 identified people with ID have autism and that information is still pending.
- SB Chatterjee stated that almost 10-15 years ago, in 2006, (at which time he worked as an architect) Autism was called TMR. He mentioned working with the data a long time ago and that systems and data have come a long way in the past 10-15 years; however there remains the need to be more

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evidence based. He indicated the importance of getting specific data. He expressed the need to use regional data for health promotion planning or health need assessments. Stamford Connecticut data for Stamford and Hartford for Hartford. He suggested initially focusing on Hartford region data county data and start from there to get a picture or a snapshot and then just look at, then we can look at other studies.

- Velandy Manohar called on members in attendance to contribute to the discussion based on identified health needs in their respective communities.
- Marlyn continued on Adrienne’s discussion on caring for children in need. She stated that one thing that stands out is the children that are not seen explaining: “when they're not seen you think about the parents so they're not seen where are.” Marilyn expressed concerned over how they are nourished, getting necessary (domestic?)Care, education, for example.
- Marlyn stated that they are not able to verbalize but raised questions as “What are their experience in the home or with the other children and the home”? “How are they being supported through this as well”? She stated that she thought “it is very important to point out the ones that are not seen and what was actually happening”? She expressed some of the some of the likely challenges experienced by parents in acquiring adequate enough food in the home. She mentioned a case to her personal knowledge, where a mother no longer goes to the grocery store with her Autistic son because on a prior visit, he eloped (escaped her custody). To assist the family, a partnership was established with a member of the community to deliver groceries to the family. Marlyn estimated that there are other mothers in the community who are not as fortunate as the one she had just cited/mentioned, stressing the need for partnership in caring for needy children in the local communities.
- Adrienne commented that Marlyn raised several important points. She recalled that for young children there's the program, “birth to 3, so you know so birth so certainly birth to three came into my life when my daughter was nine months old.” She mentioned that unfortunately, “Some parents are in denial and then there's some pediatricians who don't do the autism scale.” She also stated “...then, so after birth to three there's preschool for kids with kids that have disabilities special needs preschool and then after that there's the school system.”
- Adrienne stated that “it's not like those are wraparound services but most of those young children are in the school and hopefully are getting their needs, met through the school system.”
- Adrienne stated that some parents have their individual education plans and there are resources if the parent is able to advocate for their kids. She mentioned that some people who are disenfranchised are intimidated at a meeting to request assistance for their children. Adrienne also noted that the school systems are always low on money
- Velandy Manohar suggested that the group remember all these items, because this will come in our future meeting, indicating that we are almost out of time today for further discussions. He stated that in the next meeting, there will be next steps in focusing on the issues raised in today’s meeting.
- Terry stated that she would like to meet with Laura Morris to understand how the next health enhancement communities could be. Terry stated that listening to Adrienne report/comments and some of the ideas being presented, she wondered if the group could connect to perhaps some of those that are more organized. She repeated that she would connect with Laura to get an update.
- Velandy Manohar requested that the group have the Minutes of this meeting prepared and sent out with may give us more ideas on how to proceed. He also stated that he wanted to think about a subcommittee for the LGBTQ issues and proceed from there along with matters that Taylor and other members are involved in.

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	<ul style="list-style-type: none"> • Taylor stated that he would send you a follow up email just to make sure that he captured everything that was discussed. • Terry stated that if a small cohort want to get together and sit at her residence to work out some of these particulars she was willing to facilitate such meet. She acknowledged it is out of the ordinary to try to make things happen, but she thought most of us are bound and determined to make some something happened this year. She stated because the LGBTQ event was so successful she would not like to lose that momentum that created such success. Therefore, if members wanted to form a small group to meet and make concrete plans and then present at the next meeting, she was willing to accommodate. • Dr. Manohar: requested that the group seek guidance on meeting in person for the suggested meeting. • Terry stressed the importance of adhering to established guidelines in gathering in public places. • Ormand requested the group’s thoughts on Taylor composing elements of the survey vs a collaborative effort. • Taylor stated it might be beneficial to add a question asking people if they would like to be part of the ad hoc committee. • Adrienne acknowledged that these matters have to be announced two weeks in advance. She inquired if subcommittees have to be treated the same way. • Velandy Manohar suggested that Taylor sent by email Adrienne. The matters will be addressed in the September 14th CAC general meeting. • Velandy Manohar suggested that the next Outreach meeting be on at 3:00 PM, September 21, 2021. The meeting agreed. • Velandy Manohar requested that somebody adjourned, expressing that “we had a lovely meeting very.” • Prior to the meeting’s conclusion, Ormand assured the meetings of his commitment to help address the causes of group. He expressed that his interest in the group is motivated by his both professional passion and personal passion. He also stated that if the group thought there were any matters that he could assist with, despite his limited capacity, he would like to be told. 	
8.	Announcements/New Business	
	<ul style="list-style-type: none"> • Ormand also stated that Ms. Leslie Greer who has been out for a few weeks, will be back shortly. He stated that he was filling in for Leslie, while she was away. Ormand also stated that he would do his best in order to see a successful meeting workgroup/meeting. • Velandy Manohar stated he was very optimistic of the group’s success. • The next meeting will be held on at 3 PM, September 21, 2021 	
9.	Adjournment	4:01pm
	Meeting adjourned at 4:01 by Dr. Manohar, seconded by Adrienne	