

Consumer Advisory Board Meeting Minutes March 12, 2019

Meeting Date	Meeting Time	Location
March 12, 2019	1:00 – 3:00 p.m.	CT Behavioral Health Partnership, 500 Enterprise Drive, Suite 3D, Hartford Room, Rocky Hill

Participant Name and Attendance

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Jeffrey G. Beadle		Robert Krzys	x	Christiane Pimentel	x
Alan Coker	x	Theanvy Kuoch		Jason Prignoli	x
Alice Ferguson		Nanfi Lubogo	x	Kelly Ray	
Kevin Galvin	x	Velandy Manohar, MD	x	Ann R. Smith	
Rev. Bonita Grubbs		Arlene Murphy	x	Denise O. Smith	
Linda Guzzo		Terry Nowakowski		Stephen Wanczyk-Karp	
Others Present					
Laura Morris (OHS)		Terry Gerratana			
Leslie Greer (OHS)		Christine Bailey (UConn)			
Quyên Truong (NCRMHB)		Deb Migneault (UConn)			

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

	Agenda	Responsible Person(s)
1.	Welcome	Arlene Murphy
	<p>Call to Order The regularly scheduled meeting of the Consumer Advisory Board (CAB) was held on Tuesday, March 12, 2019 at The CT Behavioral Health Partnership, 500 Enterprise Drive, Suite 3B, Hartford Room, Rocky Hill. The meeting convened at 1:04 p.m. Arlene Murphy chaired the meeting. Members and other participants introduced themselves.</p>	
2.	Public Comment	Arlene Murphy
	There was no public comment.	
3.	Approve February 5th Meeting Summary	Arlene Murphy
	<ul style="list-style-type: none"> • No quorum 	
4.	Family Caregivers – Powerful Stories to Focus Change, UConn Center on Aging	Christine Bailey and Deb Migneault
	<ul style="list-style-type: none"> • Arlene Murphy and Linda Guzzo have spent a lot of time working to raise issues of the needs of caregivers • Christine Bailey and Deb Migneault – worked on the development of focus groups over the summer and on Money Follows the Person. • Discussed Rebalancing Initiative: which is about long-term medical services and supports. <ul style="list-style-type: none"> ○ Too much money in institutions and not enough in the communities; needed rebalancing. In 1997 received Money Follows the Person (MFP) funding in CMS – transitioned more than 5,000 people out of nursing facilities into the communities, 	

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	<p>and offers infrastructure for services in the community. Now people can live in the least restrictive environment of their choice.</p> <ul style="list-style-type: none"> ○ In December 2017, there was a Rebalancing Event. As part of this event, there was 5 major subgroups with different tasks, all of them involved support of caregivers. Linda Guzzo was part of Workforce subcommittee. ● Over summer 2018, two focus groups were conducted with 23 caregivers in CT. <ul style="list-style-type: none"> ○ Shared qualitative information – quotes on their unique struggles. What might work for their neighbors might not work for them. Often, caregivers use word-of-mouth to get information. This indicates need to get information out broadly. <ul style="list-style-type: none"> ▪ There is a lot of misinformation, particularly around Medicare/Medicaid ▪ One woman reported feeling confused about her mother’s dementia; no one told her about the symptoms. ▪ Caregivers had to learn skills of CNAs and nurses; sometimes CNAs were unreliable and quit suddenly. Caregivers are stressed and end up sick. ● Recommendations: <ul style="list-style-type: none"> ○ Establish “navigators”: designated point persons to help offer education and access ○ Provide enhanced education to access points and equip them with updated information. ○ Improve online access to information on services and supports for caregivers. For example, MyPlaceCT.org is a portal with links to community resources. ● Laura Morris asked about similarities between caregivers of people with dementia, and caregivers of parents with child with disability. She also discussed the difficult transition from childhood to adulthood for caregivers. ● Nanfi Lubogo talked about how caregiver issues are different for children and adults. It’s good to look at certain models and use them as guidance. Problem is it’s difficult to not have anything that “evidence-based” which is how you can get funding. Nanfi supports a peer model approach. ● Bob Krzys talked about training caregivers with CNAs and nurses. ● Kevin Galvin interested in idea of web training and vignettes, and think about having those in different places, in different languages. ● Dr. Manohar curious about role of advocating with provider, and whether caregiver themselves are getting help for depression. Someone needs to be educating the caregiver to be resilient long term. ● Jason Prignoli commented that there should be a more structured way to support respite care and encouraging people to seek mental health. There should be infrastructure to help monitor caregiver’s progression. ● Nanfi believes there are many ideas in recommendations that are achievable. ● Arlene Murphy stated that the group is very interested in continuing to work with caregiver researchers from UConn. Arlene can share findings with healthcare cabinet. We can share updated contact information with the CAB. 	
<p>5.</p>	<p>Consumer Feedback Loop and CAB Operating Policies and Principles</p>	<p>Arlene Murphy and Kevin Galvin</p>

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- Kevin Galvin wants to get through some of the paper we have to work with to become a new CAB with OHS. We had productive conversations in the Planning Committee, and will try to get through two of three items. In the next hour, we will hopefully wrap up operating policies and principles.
- Arlene Murphy – said this topic is about transitioning from CAB member guide and want to look at revisions needed to have CAB operating policies and principles. Will go through the list and have 6 areas to get your guidance.
- Kevin Galvin stated that the focus should be on creating a process that is sustainable and relevant.
- Arlene Murphy stated that the importance of effective consumer feedback loop is what we do, and why we do it
 - Guidance today is: is it okay for the group to have importance of effective consumer feedback loop?
 - Nanfi Lubogo stated that yes, CAB should have effective consumer feedback loop; we want recommendations, we want to know why people are coming to present, and we want to know what we will do to move the needle.
 - Arlene Murphy stated that she will take this as a yes and not belabor discussions. If there is consumer engagement it needs to be effective.
- Arlene Murphy introduced some polices to consider: consumer application process and an idea about a term of office
 - Arlene asked, now that CAB will continue past SIM, what number people are thinking? How long should a CAB member stay? One term or two?
 - Jason Prignoli commented that it's difficult to drive an agenda with 1-2 years, but perhaps 4 years is enough, and 8 years with 2 terms
 - Kevin Galvin stated that at the Planning Committee also talked about having ex-officio members; talked about 3 year term
 - Arlene Murphy stated that another option is 3 or 4 year term with ex-officio term
 - Dr. Manohar introduced the idea of an alternate schedule, so not all people leave in one year
 - Arlene Murphy looked back and there are founding members, and 4 classes of members (with 3-4 people per class). Something to consider is deciding that that founding group would end in 2020.
 - Bob Krzys stated that as a board, we should have staggered terms. It's important to focus on the transition to the OHS – they will offer administrative support. Important to focus on term limits due to recognition of personal interests – we need to be responsive to our demographics and to type of board member we may need. When we go to outreach to find the next class, we don't wind up with five attorneys. Since there have been no term limits, we should have the exit interview to share wisdom, and entrants can have an onboarding program to understand what it means to be on the CAB – clarify expectations, input.
 - Nanfi Lubogo is in favor of 2 terms of 2 years.
 - Arlene Murphy stated that there should be ex-officio status – one year position to make sure there's a good transition

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- Kevin Galvin stated that most of us have been working together for many years – so things move easily because we all have a dynamic. But as people transition in, there's still going to be work and we need new people in new categories.
- Arlene Murphy's concern was who we think might need to be in CAB might change over time. Maybe add what we need in outreach language.
- Kevin Galvin agreed that there needs to be procedure around who we want to recruit on the CAB.
- Dr. Manohar believed that 2 terms of 2 years was a good idea; people should know early on if the matching isn't going well and can drop off.
- Bob Krzys asked if there should be a screening process after 2 years?
- Laura Morris clarified that this is just the beginning process of governance structure for the CAB, need to hear from all the CAB and that consultants are here to navigate and facilitate that process and may have some suggestions for the CAB to consider.
- Kevin Galvin stated that we just want to get through the paper part today.
- Jason Prignoli mentioned the use of an easy survey monkey questionnaire to obtain input from the CAB.
- Arlene Murphy responded that we can always revisit if there are additional discussions.
- Arlene Murphy stated that we want to get some drafting based on CAB member guide – that can go back to the CAB
- Bob Krzys believes that CAB should simultaneously get input from OHS and utilize the contractors while drafting to get to yes with focused input.
- Arlene Murphy introduced discussion on co-chairs
 - Arlene asked do we want to do the same process where individuals are nominated and voted in by ballot of full CAB, and then discussion of how long are the terms.
 - Kevin Galvin commented that co-chairs should probably not cycle out at the same time. But that is my opinion only. Think you need 3 years to be effective.
 - Laura Morris stated that some committees have 4-year terms and some are appointed; there are many other things to consider regarding governance structure.
 - Arlene Murphy stated that we want to see this transition work well.
 - Bob Krzys commented that if you're going to go 2-2 on membership, and you need 3 years to be on the Chair... We should be talking about Chair, Vice Chair so the Vice Chair can be ready to move up. If we can get 17 member board, there can be a subcommittee structure that can exist: outreach, external feedback loop, internal feedback loop. Between meetings – there can be work and report back to the committee as a whole.
 - Laura Morris provided an example of how special workgroups can work.
 - Kevin Galvin stated that there are challenges with what Bob said. Workgroup subcommittees haven't worked well – we haven't done well at maintaining a full CAB presence at meetings. Workgroups are tough because people don't have the time. The Vice Chair idea is not as good because Co-Chairs means that there are 2 people making chairmen type decisions with chairmen type discussions.

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- Jason Prignoli asked if more people would come if the time were later. He is lucky in that he can take time during work hours. But more people can come after work hours.
- Kevin Galvin stated that a lot of CAB members represent groups. If we are going to bring in 2 consumers into the CAB, we have to look at transportation, location, time of day, and be sensitive to a group that isn't used to day meetings.
- Arlene Murphy commented that when we discuss this in June, from noon to 4pm, we can talk about what CAB can look like, what we can do to expand participation. Is that okay? Yes? Great.
- Alan Coker responded that we shouldn't tamper with anything. It's been working. I'd just change the terms to 3 years for the officers.
- Nanfi Lubogo supports the idea of co-chairs because it's working. 3-4 years for officers is what she'd support.
- Arlene Murphy introduced the discussion on attendance policy
 - Attend meetings, have quorum, and need to give notice that CAB members should attend by phone.
 - We have a high predominance of people with direct consumer experience, so we have to be thoughtful to them, and we need to have quorum. We have a balancing act.
 - We really want to hear whether there's a reprieve for a leave
 - Alan Coker believes we should address attendance issues
 - Nanfi Lubogo stated that we should have limits on attendance. If they cannot attend in person, they can communicate online
 - Christiane Pimentel agrees with setting process for attendance; agree with location change. Wasn't able to make it today because need to be closer to Hartford.
 - Kevin Galvin asked how do CAB members stay up to date? Members who don't come to meetings should also engage between meetings. Craft attendance policy that's about engagement rather than only meeting attendance.
 - Jason Prignoli suggested that we ask people directly whether they want to be on CAB still?
 - Kevin Galvin responded that the answer is typically no.
 - Jason Prignoli commented that it can't hurt to ask, right?
 - Arlene Murphy stated that we need to come up with attendance policy today. Her experience is that people can come to meetings. Want attendance policy that incorporates leave for personal medical reasons.
 - Laura Morris added that all committees and groups have attendance policies and continued that Jason Prignoli brings up a good point: need to talk to the absent CAB members about why they're not available.
 - Dr. Manohar offered that when we get more information, he would like to be delegated some responsibility to call other CAB members to check in with them
 - Kevin Galvin responded that is great idea and takes the authority out of it.
- Arlene Murphy introduced the idea of operating principles – similar to that of healthcare cabinet
 - Want to get a draft back to the group – add healthcare cabinet principles and apply them as a draft for CAB. Add something about consumer engagement

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	<ul style="list-style-type: none"> ○ With that guidance, we can create a draft and bring it back to CAB for the next meeting. We need to get back to consumer feedback loop. 	
6.	Updates and Other Business	Laura Morris
	<ul style="list-style-type: none"> • Jason asked if CAB members could circulate the flyer about next week’s Young Adult Event? Dr. Pearlstone will bring a virtual headset. Quyen will share the flyer with the whole CAB. • The CAB Contractor was introduced and Quyen Truong, Marcia DuFore, as well as subcontractors Tekisha Everette and Claudine Fox. 	
7.	Adjourn	Meeting adjourned at 2:41 p.m.
	Kevin Galvin motioned to adjourn and Robert Krzys seconded. Motion carried.	

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