

Online Resource 2

Patient and Family Perspectives on Accessing and Continuing Behavioral Health Services: A Qualitative Investigation

Community Mental Health Journal

Semi-structured focus group and interview guide for family members and caregivers of MassHealth members (English)

Semi-structured **Focus Group / Interview** Guide for Family Members/Caregivers of MassHealth Members

OPENING STATEMENT

My name is _____ and I work at the University of Massachusetts Chan Medical School and will be asking interview questions alongside _____ who is part of our team. (If you are a psychologist yourself, disclose that to group now)

We appreciate you taking the time to talk with us today.

PURPOSE

The goal of today's focus group is to help the Office of Behavioral Health at MassHealth better understand how members begin and stay in treatment for mental health conditions and/or substance use disorders, and what your participation is (as a family member/caregiver/friend) in these treatment efforts. MassHealth is another name for the state's Medicaid program. The information collected will be summarized into a report and shared with MassHealth to bring attention to barriers, patient's attitudes, and successes to delivering behavioral health services. We will not share your name or identifying information with MassHealth.

LOGISTICS

For today's discussion, we're planning approximately an hour to an hour and a half with a 5-minute break half-way-through. Before we get into the discussion, I'm just going to review a couple of Zoom logistics.

- We do ask that you mute yourself when not talking to minimize background noise (and don't forget to unmute yourself when you want to talk)!
- If you prefer you can use the chat box to ask any questions or make any comments – our team will be monitoring the chat box.

Also, to thank you for your time, you will receive a \$50 Bank of America gift card in the mail. **Please look out for a letter from Bank of America that will be sent a few weeks after today's sessions.**

CONFIDENTIALITY

We also want to highlight a couple of notes about confidentiality.

Before today's Zoom meeting, you should have received a **project Fact Sheet** (Note: review Fact Sheet if needed) which is like a consent form for us to speak together. As indicated in this Fact Sheet, we intend to audio-record today's session with your permission. The purpose of recording is to help us accurately

capture what everyone says. We ask everyone to respect each other's privacy and **do not** share any information you hear in this discussion outside of today's meeting.

Again, the information we learn today and from other **focus groups** will be summarized and used to prepare a report for MassHealth. Your name and any other personally identifiable information will **NOT** be used or disclosed in the report. MassHealth will not know that you have participated in these FGs/interviews on behalf of a MassHealth patient.

In a moment we will begin recording this meeting. By remaining on the call, you are giving us consent to record.

FINAL REMARKS

Before we record, a few final notes. Your participation today is voluntary; you don't have to answer a question if you don't want to. And, you don't have to answer all the questions. There are no right or wrong answers. You may also stop or withdraw from the discussion at any time with no penalty. We want to hear as many viewpoints as possible and would like for everyone to contribute their thoughts. So, please help us make sure that everyone is getting a chance to speak if they want to. There may be times that we need to interrupt the conversation just to make sure we get through all the questions and hear everyone's perspectives, so I want to apologize ahead of time if that happens.

For the purposes of today's session, we want to focus **ONLY** on your experiences as a family member/caregiver (**Note: Tell group that you'll be using 'family member' moving forward, but that some of the participants may be 'caregivers' for a MassHealth patient**). We **DON'T** want you to share your own experiences if you have received treatment yourself; we only want to know about the experiences of your family member.

Are there any questions before we begin? [**Pause and answer as needed**]

I'm going to begin recording now.

QUESTIONS

[Icebreaking and Background Questions]

Today we will be asking you about "behavioral health services." Some people refer to these services as "mental health treatment" or "substance use treatment." Typically, this care is delivered by one of the following types of providers: a psychiatrist, or psychiatric nurse practitioner, a clinical social worker, or a clinical psychologist. Some people also have the behavioral health care addressed by their primary care provider. Some people may simply refer to their provider as a "counselor" or a "therapist." While we recognize that many people receiving behavioral health care also have medical or physical health problems, today we are focused on understanding more about the *behavioral health care* they receive, *not the medical care*.

- 1) First, I'd like to ask for you to introduce yourself using your first name only and share your relationship to the MassHealth member receiving behavioral health services. Also, describe briefly what types of behavioral health services the MassHealth family member is receiving (to the extent that you know this information). Would someone like to volunteer to start?

[Main Questions]

We'd like to ask about your experiences as family members and caregivers to someone who **used behavioral health treatment for the first time.**

- 2) How did you (as a family member) get involved in their behavioral health treatment?
 - a. What is your role in their care?
- 3) What do you know about how your family member got connected with behavioral health treatment?
 - a. Have you ever been the one to request care for your family member? If so, how did that go?
 - b. Has your family member asked you for any assistance getting connected to BH care? What have they asked you to help with?
- 4) When your family member started behavioral health treatment, what was that initial experience like?
 - a. Was it positive? How so?
 - b. Was it negative or not what was expected? Why?
 - c. Did treatment begin quickly or take a lot of time?
 - d. Did anything change or get better/worse?
- 5) To your knowledge, did the behavioral health provider that your family member was meeting with communicate with other health care providers of theirs? How did they communicate?
- 6) Did the provider work to include you or others in your family member's care? In what way(s) were you included?
- 7) Did your family member have a preference for a behavioral health provider who spoke a language other than English?
- 8) For my next question, let me start with some examples. Sometimes, people want to have a provider who is similar to them in some way: such as.... if someone is Hispanic, that patient might have a preference for a provider who is also Hispanic. Or, someone who is gay may want a counselor who is gay. Has your family member had a provider who was different from his/her preference? Do you know if that was an issue for your family member or not? What factors of a counselor's identity are important to your family member in terms of culture, race, ethnicity or sexual identity.

Next, we'd like to ask about your experiences as family members as your family member **continued to receive behavioral health treatment.**

- 9) Can you describe anything that made it difficult for your family member to stay connected with behavioral health treatment?

- a. (Note: Only probe if there's no response; give a few examples) Barriers to access might include unreliable transportation, unaffordable health care costs, long wait times, insufficient support from health care staff, stigma, among others.]
 - b. Can you describe any time your family member didn't or couldn't get to appointments (Note: Only probe if there's no response; e.g., transportation, scheduling issues, costs, family priorities)?
- 10) Have there been times when your family member didn't want to go back to a behavioral health provider? Can you explain why?
- 11) What would help your family member to remain with behavioral health treatment?
- a. Some things that might help or facilitate engagement include flexibility with scheduling and meeting times, transportation accommodations, financial assistance or incentives, support from staff, and support from friends and families]

Next, I'd next like to next ask you about your level of involvement in your family member's care.

- 12) Have there been times when your family member specifically asked you to not be part of their care team (i.e., to let them do things themselves)? If so, do you think they would have benefitted more if you were involved? (Note: Ask the next 2 questions as individual questions)
- a. If you weren't involved early on for your family member, did you become more involved over time?
 - b. Have there been times when your family member wanted to stop treatment, but you intervened in a way that kept them in treatment? Can you elaborate on how you made this happen?
- 13) Thank you for your participation throughout this discussion. We've learned a lot! I have one final question: Sometimes we want families to be involved in treatment, but we also want to respect a patient's right to privacy. What thoughts do you have about how to balance the right to privacy with involving family members in care?
- a. If you're engaged with their care, do you think it's vital that provider(s) share personal information with you?
 - i. Are there situations where you think providers shouldn't share vs some situations where you think providers absolutely should share information with you?
- 14) Is there anything else you would like to say before we close today's focus group?

CLOSING

Those are all the questions we have for you. Thank you all for volunteering to share your experiences and perspectives with us! We really appreciate your time and input. If you have any additional comments or questions about our evaluation and would like to follow up with us, please feel free to reach out to me via email _____ or call _____.

Again, please look out for a letter in the mail from Bank of America with your gift card. Thank you!