

Attachment B7: Family/Caregiver Focus Group Discussion (FGD) Pilot Test Results

Health Resources and Services Administration (HRSA) Maternal and Child Health Bureau (MCHB) Pediatric Mental Health Care Access (PMHCA) Program National Impact Study

Note: The instruments included in this OMB package have been revised and incorporate the pilot test results.

Feedback	Changes Made to Instrument, if Applicable
General Feedback	
<p>Time to complete:</p> <ol style="list-style-type: none"> 1. I would guess 30-45 minutes with 5-7 participants. 2. 45? 3. Anywhere from 45 to 70 minutes depending on how comfortable and talkative participants are and how well they understand what is being asked. They will give shorter answers if they aren't quite sure they know what you want. If there are people for whom English is not their first or preferred language it will be on the longer end. 4. 45 - 60 minutes 	<p>Projected time to conduct the FGD will stay the same at 60 minutes</p>
<p>How clear and easy to understand are the survey instructions and questions?</p> <ol style="list-style-type: none"> 1. Instructions and questions were clear, some could use more guidance. 2. Fairly clear 3. They are clear and easy to understand 	<p>Minor revisions were made throughout the guide to improve clarity.</p>
<p>Were there any issues with the flow, formatting, layout, or appearance of the survey? If so, please explain.</p> <ol style="list-style-type: none"> 1. None 2. I wonder whether it would first make sense to focus on primary care, and then issues related to access and delays w specialists, and then specialists. 3. Might start with the general communication question since it is broader than the others and might let people warm up a little. 4. I think question 1 should come after questions 2 and 3. I think you want to 	<ol style="list-style-type: none"> 1. N/A 2. Revised. 3. Revised. 4. Revised.

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<p>get people talking about how the describe their concerns in a more open ended way before asking them what needs have not been met</p>	
<p>Do you foresee any challenges or barriers to conducting an online (via Zoom or Microsoft Teams) focus group discussion? If so, please explain.</p> <ol style="list-style-type: none"> 1. There will be participants that talk too much and go into more detail than needed. Facilitator should be prepared to kindly know how to shut that down and move on. 2. Not particularly though would make sure that people have headphones, find out who else is in the room/encourage private space etc. 3. People who have less access to broadband internet may not be as used to the environment. Whether or not they have privacy and are free of interruptions will also impact comfort. 4. These are caregivers who may have multiple children/competing demands/distractions at home. It may be challenging to maintain active engagement across all participants in their homes. 	<ol style="list-style-type: none"> 1. N/A 2. Added bullet in the introductory guidelines to address participating in a quiet area and using headphones, if needed. 3. N/A 4. Added bullet in the introductory guidelines to address participating in a quiet area and using headphones, if needed, but understand that not all participants will be able to limit distractions.
<p>Please provide any additional comments or suggestions to improve the survey (e.g., unnecessary or missing questions or response options; spelling/grammatical errors; sensitivity issues).</p> <p>N/A</p>	<p>N/A</p>
Survey Question Feedback	
<p>I'd like to start by asking each of you to introduce yourself. Please tell us your first name and the age(s) of your child/children for whom you have sought behavioral health care. As a reminder, please don't share your child's name or any other detailed personal information.</p> <p>Thank you. Before starting our discussion, I'd like to explain some</p>	<ol style="list-style-type: none"> 1. Revised definition. 2. Kept as "your" to get at the child/adolescent they are seeking services for. 3. Revised.

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<p>terms that we'll use.</p> <ol style="list-style-type: none"> 1. Is this only discussing behavioral health care? Mental Health and behavioral cross over together so curious about that. If so, it should be added. 2. I think "the child/children for whom" is more correct or at least sounds better. Also might be a good idea to de-emphasize "your" since the survey is for caregivers as well as parents. 3. I would define "behavioral health specialist" after defining "behavioral health care" and before "primary care health professional." Can "behavioral health care" include BH care provided by a PCP? If so, it may be important to say "any health professional including behavioral health specialists or primary care professionals" in the first bullet point. 	
<p>How well do you feel your child's behavioral health needs are being met?</p> <ol style="list-style-type: none"> 1. I'm not sure if meeting BH needs means mean logistically or if you are asking about effectiveness. You may get insurance coverage/prior auth[orization] issues here. Maybe that's okay. 	<ol style="list-style-type: none"> 1. Revised with modifications to facilitate open discussion.
<p>What has been your experience with accessing behavioral health services for your child?</p> <p>a) PROBE: Were you given an opportunity to share your behavioral health concerns with your primary care health professional? Did you feel listened to?</p> <p>b) PROBE: How did your primary care health professional or professional's practice learn more about your child's behavioral health concern? How was the information communicated with you?</p> <ol style="list-style-type: none"> 1. I don't think people think of finding and getting in to see a provider as "accessing." Consider defining PCP as the term you will use so you don't have to say primary care health professional 	<ol style="list-style-type: none"> 1. Revised to PCP; revised "access" to "getting"; added questions related to school and emergency departments. 2. Moved as recommended. 3. Moved as recommended.

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<p>or professionals over and over again. The probes seem to be about the interaction with the PCP but the overarching question is about accessing BH services which may or may not lead to a discussion of the PCP. Sort of assumes they started with the PCP and not a crisis center or school or something. Maybe you are trying to find out what it was like to ask for help or share your concerns about the child's BH?</p> <ol style="list-style-type: none"> 2. Maybe this question should go before q[uestion] 1. First ask how you share concerns and then whether there are concerns that have not been met. 3. I would ask this question first (before question 1). 	
<p>What has been your experience getting behavioral health care for your child from a specialist when it was needed?</p> <p>a) PROBE: What has been your experience connecting with a behavioral health specialist? Did you get help from your primary care health professional or a care coordinator?</p> <p>b) PROBE: Have you had delays in accessing behavioral health specialists? For which kinds of specialists did you experience a delay in accessing?</p> <p>c) PROBE: What has been your experience getting prescriptions to treat your child's behavioral health concern when needed? Did you experience delays or other challenges?</p> <ol style="list-style-type: none"> 1. From the wording, not clear how this is different from question #2. Is question # 3 about the actual experience in treatment and #2 about accessing treatment (in which case delays might be a better probe there)? 2. Connecting and accessing are not words people use to talk about finding a provider and getting in to see one. Also, the question is worded as if it is assumed they have sought care from a specialist. What if they haven't? What if they tried and failed? 	<ol style="list-style-type: none"> 1. Revised questions to provide clarity. 2. Revised language to provide clarity. 3. Added question related to barriers.

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<p>3. I would add barriers - what barriers and delays have you had in accessing behavioral health specialist.</p>	
<p>What has been your experience in receiving health services that are respectful of your culture and language preference?</p> <p>a) PROBE: How have you and your primary care health professional communicated about your cultural beliefs as they relate to your health care?</p> <p>b) PROBE: How have your needs for language preferences, if any, been addressed by your primary care health professional?</p> <p>c) PROBE: Have the materials and communication with your health professional been clear and easy to understand? Why or why not?</p> <p>1. This question assumes that the services were respectful of culture and language preference? I wonder whether the first probe would be better overall question.</p> <p>2. If you are asking more broadly about the interaction and don't mean this question to be specific to BH you might want to be more explicit in the transition statement. Are you still asking about the child? These are worded as if we are now asking about the caregiver. The last probe here about clear and easy to understand is broader than question 4 as it is currently written. Maybe "How easy or difficult has it been to communicate with or understand your PCP?" with a probe about how did cultural beliefs impact communication such as: How did language preferences (what about straight out needs) impact communication? Are you prepared to have someone in these focus groups who prefers to communicate in a language other than English? If they communicate comfortably in English how likely is it language will be a problem in communicating with the</p>	<p>1. Revised.</p> <p>2. Revised to improve clarity. Focused on PCP, as the goal of the PMHCA program is to integrate behavioral health care in the primary care setting. Interviews will be conducted in English; however, it is possible that English is not the primary or preferred language for some participants.</p> <p>3. Did not add, captured in other questions.</p>

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<p>provider? Why are is this question limited to the PCP?</p> <p>3. Could add do you believe your priorities and your PCP's priorities match? Culture can affect the health care priorities.</p>	
<p>How has receiving behavioral health care for your child affected your child's day-to-day life?</p> <p>1. There wasn't a transition between this and the primary care question- would make sure clear delineation of transition between two types of care/settings.</p> <p>2. How has meeting the child's behavioral health care needs affected you and your child's day to day life? The question assumes the feel that they feel are successfully getting behavioral health care. My wording assumes they think the needs are met though. Is there a reason you are only asking about how the child's life is impacted and not also the caregiver? Are people going to understand behavioral health care may be what the PCP is doing? They might think they are not getting behavioral health care because they are not seeing a specialist?</p> <p>3. This is pretty open ended: maybe add positively and negatively or something to give more guidance.</p>	<p>1. Added transition text.</p> <p>2. Modified revisions based on recommendation.</p> <p>3. Revised.</p>
<p>Overall, how satisfied are you with the behavioral health care you received from your child's primary care health professional? Why?</p> <p>1. Make sure ask separately about behavioral health care in primary care (vs specialist)?</p>	<p>1. Revised.</p>
<p>Is there anything else you would like to share relevant to our discussion today?</p> <p>1. "relevant to our discussion" is a little odd. As if you are heading off all the irrelevant stuff you expect them to bring up. "Is there anything else you would like to share about your experience with getting behavioral health care for the child?"</p>	<p>1. Removed.</p> <p>2. We will not include this question because we will not be able to change the guide once it receives OMB approval.</p>

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2. Could also ask if there are questions that we should be asking but did not.	