

Attachment K. Focus Group Discussion Guide for Parents/Caregivers and Young Adults

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BIRCH Focus Group Discussion Guide For: -Parents/Caregivers -Young Adults

Consent Review and Survey (for in-person Focus group only)

- Thank you for joining our focus group discussion today!
- As others join, we would like you to review and sign the consent form for this study [*provide consent form*]. Would you like any support to go through this document? [*if yes, read consent to participant*].
- We would like to review some key parts of the consent form together. [*Briefly verbally review the key parts of the consent form including purpose and use of study data, confidentiality parameters and data security, and opportunity to decline at any time. Be sure to emphasize that information is kept confidential and personal information is stored separately than their responses today, helping to preserve anonymity. Note that the audio recording will be destroyed soon after a transcript is produced*].
- Do you have any questions? Please take your time and feel free to ask any questions you have as you read through it. After you have reviewed the consent form and the research team has adequately addressed any questions or concerns you have, please sign and return the form to [*insert name*]. These signed consent forms will be stored separately from the other information so your names will never appear with the information you provide.
- [*Once the consent form is signed, administer the survey.*] Thank you! This is a brief survey to help us describe, as a whole, the people we speak with in this study. These data will be combined to describe participants as a group. You will not be identified personally. [*Administer survey – either by having participant read and complete individually or if support for consent process was sought by participant, community researcher to read each item and responses aloud and assist participant to complete survey*]. Please let me know if you have any questions about any of the survey questions or response options. You can choose to skip or not answer any question for any reason. You can also decide to not complete this survey and still participate in the discussion today.

Opening Blessing and Activity – (e.g., cultural activity, land acknowledgement) [*Facilitated by community researcher; Will work with the facilitator to determine whether this should come before or after introductions*]

Permission to Record

As we indicated in the consent form and invitation we would like to (audio) record this discussion. The recording will be destroyed after we are able to prepare the transcript or notes from the discussion. Are there any questions about the recording? Ok, I will begin the recording now [*Begin recording*].

[If anyone refuses recording] OK, instead my study assistant [*insert name*] will take detailed notes. [*Begin note-taking*].

Introduction

Hello, [*Name/Names*]. I'd like to thank you for taking the time to join me today for this group discussion. [*Introduce all facilitators*] My name is [*Insert name*]. I am/we are a researcher with [*insert organization or institution and a very brief description of focus of research/experience*]. This discussion is part of a study that is funded by the Centers for Disease Control and Prevention to understand how health and well-being are supported in urban and rural Native communities.

As part of this study, we are talking to many people in your community, including [*parents and caregivers or young adults*], such as yourself, as well as talking to [*parents and caregivers or young adults*] and community and tribal leaders.

You have been invited here today because of the knowledge you hold about [*insert Tribe or urban Indian community name*] from growing up and living here. We appreciate the opportunity to learn from you to understand how your community keeps children and families safe and happy and healthy.

We will ask some questions to help start the conversation but will really have this space as an opportunity for us to learn from you. We will spend about 90 minutes together. The flow of the conversation will be as follows. We will start with introductions, then pose some questions about positive childhood experiences in this community, then turn to community prevention of adverse childhood experiences and substance use, recovery and healing journeys from substance use, and we will end with your ideas about opportunities to enhance prevention of trauma and substance use.

Could we go around and have everyone introduce themselves and share anything you feel would be helpful or important as we start our discussion today?

[*Allow everyone time to share*] Thank you!

Expectations

Before we start with our discussion, I would like to describe what we mean by focus group. To better understand a specific issue, researchers often bring together people who have knowledge or experience with the issue so that they can have a rich conversation. In today's discussion, we would like to hear your voices, perspectives, and experiences to understand what is helpful in your community in supporting children and families' health and well-being.

To facilitate this discussion, we will ask questions to guide the discussion. We want you to feel comfortable sharing openly and as much as you like, while still creating space for all of your voices. This way we can hear from each of you and better understand the issue. As you can see, there are [*insert # of people*] of us in the discussion and so we will need to set some expectations that will help us create this kind of safe and inclusive space.

Our research team has established some expectations that we feel might help our discussion. We have listed these on this [*whiteboard/large post-it paper*] here (*show previously prepared list*). We can start with these and then open it up for everyone to add more:

- (1) We ask that you respect everyone's privacy and not share anything said here outside of this room.
- (2) We encourage you to share only what you are comfortable sharing.
- (3) Please allow the person speaking to complete their thoughts and story.
- (4) We ask that everyone be courteous to other participants and consider how much time you are speaking to allow everyone else time to share.
- (5) Also, please remember that you are free to respond or not respond to any questions. If you need to take a break at any time, for any reason, please feel free to do so.
- (6) We also ask that you respect the privacy of individuals not participating in the group. If you would like to share a story or experience about someone you know, please refrain from identifying them by name.

Are there any other expectations you would like added to our discussion today? [*Pause and add expectations as appropriate to whiteboard*]

Does anyone have any questions about these expectations or more generally about our discussion today? [*Pause and answer questions if asked*]. If you have any questions during the discussion, please know that you can ask them at any time.

COMMUNITY PROMOTION OF POSITIVE CHILDHOOD EXPERIENCES

Let's begin by discussing how your community helps support community wellness and positive childhood experiences.

1. What is great about growing up in [*insert Tribe or urban Indian community name*]? [*Introduce the whiteboard feature*] I am going to use the whiteboard to write down what I hear about positive childhood experiences. Feel free to let me know if I miss something or get something wrong. [*list positive childhood experiences*]

o *Clarifying question:*

- What are examples of ways the community helps children to grow up happy and healthy in *[insert Tribe or urban Indian Community name]*? Some ways communities may support children could be, for example, through activities for families, early care settings or schools, community programs or institutions, or cultural practices that help to keep children healthy and strong.
 - *Follow-up questions:*
 - How else does *[insert Tribe or urban Indian community name]* support health and well-being for *[children and families / youth and young adults]*? Some ways communities may support health and well-being could include, for example, providing a lot of opportunities for community members to gather, hosting traditional events, or connecting community members to resources to have a safe home environment. I am going to continue to write down what I hear on the whiteboard. *[list health and well-being promotion efforts]*
 - How do the positive experiences in childhood from our list affect health and well-being in this community?
 - *Probes:*
 - **Examples** - *when needed to more fully understand the concept*
 - Tell me more about *[resource or support]*.
 - Could you describe a specific example of *[resource or support]*?
 - **Cultural practices:** - *defer to community researcher about appropriateness*
 - In what ways might cultural activities or practices contribute to children's positive experiences in *[insert Tribe or urban Indian community name]*?
 - How does *[insert Tribe or urban Indian community name]* support children's and youths' participation in cultural practices?
2. We have generated a solid list of positive experiences and ways they support health and well-being. What challenges or barriers gets in the way of communities making these positive experiences available and accessible to all *[children and families / youth and young adults]*?
- *Probe:*
 - **Overcoming challenges:**
 - How might *[insert Tribe or urban Indian community name]* go about trying to overcome the challenges and barriers?

COMMUNITY PREVENTION OF ACES AND SUBSTANCE USE

Now, we would like to talk about efforts that are focused on helping people and communities prevent adverse childhood experiences and substance use – to keep them from happening or reduce how often they happen. In our discussion today, when we refer to adverse childhood

experiences or adversity, we mean experiences that can cause trauma such as physical or emotional harm, neglect, family conflict, historical trauma, and racism.

3. How does [*insert Tribe or urban Indian community name*] help prevent [*children and families / youth and young adults*] from experiencing adverse childhood experiences and trauma? I am going to use the whiteboard to write down what I hear about prevention resources or strategies. Like before, please let me know if I miss something or get something wrong. [*list prevention strategies and resources*]
 - o *Clarifying question:*
 - For example, one way could be having a particular characteristic or quality of the community, such as a foundation of multi-generational households. Or, another could be a specific thing that community members do or have access to, such as parenting resources, or governmental commitments to addressing poverty. What does [*insert Tribe or urban Indian community name*] do or provide to protect [*children and families / youth and young adults*] from having negative or harmful experiences?
 - o *Follow up questions:*
 - o How might these resources and strategies that we have listed today also work to prevent or reduce substance use? [*note which listed prevention resources or positive childhood experiences are also discussed as strategies for substance use – e.g., with an asterisk*]
 - o What additional ways does [*insert Tribe or urban Indian community name*] work to prevent or reduce substance use among [*children and families / youth and young adults*]? [*list additional efforts and resources that are mentioned for substance use*]
 - o *Probes:*
 - o **Examples** - *when needed to more fully understand the concept*
 - Tell me more about [*resource or support*].
 - Could you describe a specific example of [*resource or support*]?
 - o **Cultural practices:** - *defer to community researcher about appropriateness*
 - In what ways might cultural activities or practices in [*insert Tribe or urban Indian community name*] contribute to the prevention of adverse childhood experiences and substance use?
 - How does [*insert Tribe or urban Indian community name*] support [*children and families' / youth and young adults'*] participation in these cultural practices?
 - o **Mechanisms:**
 - How do you think [*resource/program/service*] is beneficial to preventing substance use and adverse childhood experiences/trauma?

4. We've added to our list(s) ways that [*insert Tribe or urban Indian community name*] prevents or reduces negative childhood experiences and substance use. What challenges or barriers might get in the way of communities making these prevention efforts or resources available and accessible to all [*children and families / youth and young adults*]?

o *Probe:*

▪ **Overcoming challenges:**

- How might [*insert Tribe or urban Indian community name*] go about trying to overcome the challenges and barriers?

SUBSTANCE USE RECOVERY

There are various ways people overcome trauma and substance use. Some language that is used to describe this process is 'recovery' and 'healing journey.'

5. For individuals in [*insert Tribe or urban Indian community name*] who have worked to overcome trauma or substance use on a healing journey, what resources or supports helped them heal?

o *Clarifying question:*

- What helps families and young adults here recover from traumatic experiences and substance use?

o *Probes:*

o **Examples** - when needed to more fully understand the concept

- Tell me more about [*resource or support*].
- Could you describe a specific example of [*resource or support*]?

o **Response to both trauma and substance use** – if respondents only speak to one of these, ask about the other

- What resources and supports help a person heal from [*trauma / substance use*]?

o **Cultural practices:** - defer to community researcher about appropriateness

- In what ways might cultural activities or practices in [*insert Tribe or urban Indian community name*] contribute to a person's healing journey?
- How does [*insert Tribe or urban Indian community name*] support [*children and families' / youth and young adults'*] participation in these cultural practices?

o **Mechanisms:**

- How do you think [*resource/program/service*] helps individuals recover from substance use and ACEs/trauma?

6. What challenges or barriers have you seen get in the way of a persons' or family's healing journey?

- o *Probe:*
 - **Overcoming challenges:**
 - How might [*insert Tribe or urban Indian community name*] go about trying to overcome the challenges and barriers?

OPPORTUNITIES TO ENHANCE PREVENTION

7. If anything was possible, what more would you have [*insert Tribe or urban Indian community name*] do to support well-being and healing journeys?
 - o *Clarifying question:*
 - If resources were unlimited, what supports, resources, services or other factors might be needed or helpful in [*insert Tribe or urban Indian community name*] in breaking the cycle of both childhood trauma/adversity and substance use?

Thank you for taking the time to share with me today. Those are all the questions I have for you.

Is there anything else you would like to add to our discussion before we end?

Thank you again. I'm going to [end our recording/stop taking notes] now [*End recording and notetaking*].

After we are done hearing from members of [*insert Tribe or urban Indian community name*] and have a chance to begin summarizing the information, we may circle back with you to make sure our understandings of what you shared today are correct. This may be over email or a quick phone call. Are you willing to be contacted later? We will keep your contact information separate from other information you have provided to protect confidentiality. [*If yes, check that we have their phone number and email address; if we do not, please ask for it*]

[*Share any additional information about dissemination protocols identified through the Data Sharing Agreement with the community*]

Closing activity (e.g., blessing, cultural activity) [*facilitated by community researcher*]