

Informed Consent for Research Participation

IRB #: AG23-01

IRB Approval Date: January 8, 2024

Attachment B5:

Family/Caregiver Focus Group Discussion Consent Form

JBS International, Inc. (JBS)
Informed Consent for Focus Group Discussion (FGD) Participation
Health Resources and Services Administration (HRSA) Maternal and Child Health Bureau (MCHB)
Pediatric Mental Health Care Access (PMHCA) Program National Impact Study

Study Title: HRSA MCHB PMHCA Program National Impact Study

Researchers: HRSA MCHB funded JBS to conduct the Impact Study.

We (the study team at JBS) are inviting you to participate in a focus group discussion or FGD as part of research. Participation is completely voluntary. If you agree to participate now, you can always change your mind later. There are no negative consequences, whatever you decide.

What is the purpose of this study? The study's purpose is to gather your insights and opinions about your experiences with getting behavioral health care for your child/adolescent and its impact on your family and child/adolescent. The information collected will be used to help our understanding of HRSA's Pediatric Mental Health Care Access (PMHCA) program—specifically how PMHCA improves access to and receipt and use of behavioral health care, as well as behavioral health impacts. You may not be familiar with the PMHCA program, but your primary care health professional may be participating. Findings from the study may help to improve HRSA MCHB PMHCA programs and be used to support future decisions regarding the program and similar programs.

What will I do? If you agree to participate in the study, you will be asked to first sign and date this consent form. Your participation will consist of participating in an approximately 1-hour long virtual focus group discussion with about 5-6 other people.

We will encourage you to turn on your device's camera during the discussion, but it's not required. The study team will record the FGD for the purpose of reviewing and reporting on the information collected.

Risks:

- There may be some questions you do not feel comfortable answering. It's okay to not discuss certain topics; please only speak as openly as you feel comfortable.
- If you choose to turn on your camera during the discussion, there's a risk that someone may recognize you. You will not be required to turn on your camera.
- If you do not update your display name on the virtual platform (e.g., Microsoft Teams or Zoom) prior to joining the FGD, there is a risk that your full name would be displayed and that someone may recognize you. If you do not want your full name to appear, please update your display name before joining the FGD.
- During the discussion, you will be asked to share your first name (or preferred name) and the age(s) of your child(ren)/adolescent(s); you will not be required to share this information during the discussion if you do not feel comfortable.
- There is a chance that your information could be seen by someone who shouldn't have access to it. We're minimizing this risk in the following ways:

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- We'll store all related information on a secure, password-protected server at JBS.
- Data are stored with direct identifiers, but your identity will not be disclosed to anyone outside the research team.

Possible Benefits: There is no direct benefit to you because of participation. Our hope is that the information learned from this study will improve the PMHCA program and ultimately improve access to behavioral health care.

Estimated Number of Participants: Approximately 5-7 adult family members or caregivers will participate in each FGD, and up to 6 focus groups will be conducted, for a maximum of 42 participants.

How long will it take? Your participation in this study will be approximately 1 hour. You may stop your participation at any time.

Costs: Your cost is the time it takes to participate in the FGD and any data or connection charges associated with remote participation using your phone, computer, or tablet.

Compensation: You will receive \$25 for participating in the FGD.

Future Research: We will share de-identified data (all identifying information removed) with HRSA. No future studies are currently planned.

Recordings: We will record the FGD for the purpose of the study team reviewing and reporting on the information collected. Turning on your camera during the discussion is optional. If you do not want to be recorded, you should not participate in this study.

Funding Source: HRSA MCHB is funding this study.

Confidentiality and Data Security: During the FGD, we will ask you to introduce yourself by first name only (or your preferred name) and to share the age(s) of your child(ren)/adolescent(s); however, you will not be required to share this information.

Prior to this consent form, we collected the information below from you over the phone for FGD scheduling and data analysis purposes.

- First and last name
- Contact information
- ZIP Code
- Preferred language
- Age(s) of child(ren)/adolescent(s)
- Race/ethnicity of child(ren)/adolescent(s)
- Gender identity of children(ren)/adolescent(s)

Where and for how long will data be stored? The FGD recording and a transcript of the recording as well as the information that we collected from you over the phone will be stored on a secure, password-protected server at

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JBS. We will destroy the FGD recording after we finish creating the transcript. The transcript and information that you previously shared with us over the phone will be stored for 10 years.

Who can see my data?

- We will have access to identifiable data (with your name included). This is so we can conduct the study.
- Your name may be visible during the FGD; however, you can avoid this by updating your display name prior to joining the FGD.
- We may share our findings in reports or presentations. If we do, the results will be grouped data, with no individual results or identifying information.
- Agencies that enforce legal and ethical guidelines, such as
 - The Institutional Review Board (IRB) at JBS
 - The Office for Human Research Protections (OHRP)

Questions About the Research, Complaints, or Problems: For questions about the study or if you have problems or concerns, contact Amanda Gmyrek by email (agmyrek@jbsinternational.com) or by phone (240-645-4848).

Questions About Your Rights as a Research Participant, Complaints, or Problems: Contact the JBS Institutional Review Board at kfranke@jbsinternational.com or mhyary@jbsinternational.com

Agreement to Participate:

Your participation is completely voluntary, and you can withdraw at any time.

To participate, you must be:

- A parent/caregiver who has sought and/or received behavioral health care for your child(ren)/adolescent(s) ages 0-21
- At least 18 years old
- Have access to a phone, computer, or tablet with internet access

Signatures

If you've had all your questions answered, meet the criteria listed above, and would like to participate in this study, please sign on the lines below. Remember, your participation is completely voluntary, and you're free to withdraw from the study at any time.

Name of Participant (print)

Signature of Participant

Date