INFORMED CONSENT FORM

Study Title: What Is the Lived Experience of Adoptive Mothers Who Are Raising Children Diagnosed With Fetal Alcohol Spectrum Disorder (FASD)? A Phenomenological Approach

Researcher: Denise Milne

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Research Supervisor: Dr. Greenstone

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You are invited to be part of a research study. The researcher is a doctoral learner at Capella University in the School of Psychology. The information in this form is provided to help you decide if you want to participate. The form describes what you will have to do during the study and the risks and benefits of the study.

If you have any questions about or do not understand something in this form, you should ask the researcher. Do not sign this form unless the researcher has answered your questions and you decide that you want to be part of this study.

ABOUT THE RESEARCHER

The researcher is a doctoral learner at Capella University’s Harold Abel School of Social and Behavioral Psychology and the Senior Manager of the FASD-Cross Ministry Committee. In my administrative role with the Government of Alberta, I am responsible for the implementation of the FASD 10-Year Strategic Plan in Alberta. The Coordinator/Executive Director of the FASD Service Network has permitted has permitted me to bring this study to your attention in the event you may be interested. However, the FASD Service Network Coordinator/Executive Director in your area remains neutral with regard to your decision to participate or decline to participate in this research study.

WHAT IS THIS STUDY ABOUT?

The researcher wants to learn about adoptive parents who are raising a child diagnosed with fetal alcohol spectrum disorder (FASD) to understand the lived experience. The age of your child does not matter. The child or children do not have to be living with you.

WHY AM I BEING ASKED TO BE IN THE STUDY?

You are invited to be in the study because you are:

- An adoptive mother raising a child medically diagnosed with FASD.

All participants will be between 18 and 65 years of age. If you do not meet the description above, you are not able to be in the study.
HOW MANY PEOPLE WILL BE IN THIS STUDY?
About 8 participants will be in this study.

WHO IS PAYING FOR THIS STUDY?
The researcher is not receiving funds to conduct this study.

WILL IT COST ANYTHING TO BE IN THIS STUDY?
You do not have to pay to be in the study.

HOW LONG WILL I BE IN THE STUDY?
If you decide to be in this study, your participation will last about 2 to 3 hours. You will determine the length of time. The interview will take place in a neutral location such as a meeting room in a local library. Participation in the study will occur once, and you will have an opportunity to review the transcript from our interview. The researcher, Denise Milne, will audiotape the interview and take some notes with your permission.

WHAT WILL HAPPEN DURING THIS STUDY?
If you decide to be in this study and if you sign this form, you will:

- Answer questions about your experiences as an adoptive mother of a child diagnosed with FASD.
- Come to a meeting room at a neutral location such as a local public library.
- Review a copy of your transcript (if desired).

While you are in the study, you will be expected to:

- Follow the instructions you are given.
- Tell the researcher if you want to stop being in the study at any time.

WILL I BE RECORDED?
The researcher will audiotape your interview and use the audiotape to ensure accurate records of the conversation. The tapes will be transcribed (typed) for the purposes of reading and analysis. Your identity will be protected. Any e-mail correspondence with the researcher will be destroyed. A code number will appear on your tape to allow the researcher to keep track of the interview. Only you and the researcher will know the code number.

The researcher will use your recording only for the purposes you read about in this form. She will not use the recordings for any other reasons without your permission unless you sign another consent form. The recordings will be confidential and will be kept for 7 years. They will be destroyed after 7 years.

WILL BEING IN THIS STUDY HELP ME?
Being in this study will not help you. Information from this study might help researchers to help others in the future.
ARE THERE RISKS TO ME IF I AM IN THIS STUDY?

No study is completely risk free. However, we do not anticipate that you will be harmed or distressed during this study. You may stop being in the study at any time if you become uncomfortable.

WILL I GET PAID?

If you participate, you will receive a $50 gift card from Tim Hortons.

DO I HAVE TO BE IN THIS STUDY?

Your participation in this study is voluntary. You can decide not to be in the study, and you can change your mind about being in the study at any time. There will be no penalty to you. If you want to stop being in the study, tell the researcher. The researcher can remove you from the study at any time. This could happen if:

- The researcher believes it is best for you to stop being in the study.
- You do not follow directions for the study.
- You no longer meet the inclusion criteria to participate.

WHO WILL USE AND SHARE INFORMATION ABOUT MY BEING IN THIS STUDY?

Any information you provide in this study that could identify you, such as your name, age, or other personal information, will be kept confidential. The information from the study will be saved on a computer hard drive and a USB memory disk. The only person who will have access to the information is the researcher. All information stored on the computer will be secured in the researcher’s private office. There will be no identifying information in the taped interviews or on the transcripts and no one other than the researcher will be able to connect a participant with specific information. In any written reports or publications, no one will be able to identify you.

The researcher will keep the information you provide on a password-protected computer and a locked file cabinet in her private office, and only the researcher will be able to review this information. If you leave the study early, the researcher will not be able to use your data.

Limits of Privacy (Confidentiality)

Generally speaking, the researcher assures you that she will keep everything you tell her or do for the study private. However, at times the researcher cannot keep things private (confidential):

- If the researcher finds out that a child or vulnerable adult has been abused
- If the researcher finds out that a person plans to hurt him- or herself, such as commit suicide
- If the researcher finds out that a person plans to hurt someone else.

Laws require many professionals to take action if they think a person might harm him- or herself or another person, or if a child or adult is being abused. In addition, researchers must follow guidelines to ensure that all people are treated with respect and kept safe. In Alberta a government agency must be told if someone is being abused or plans to hurt him- or herself or another person. Please ask any questions that you might have about this issue before agreeing to participate in the study. It is
important that you not feel betrayed in the eventuality that the researcher cannot keep some things private.

**WHO CAN I TALK TO ABOUT THIS STUDY?**

You can ask questions about the study at any time. You can call the researcher if you have any concerns or complaints. You should call the researcher at the phone number listed on page 1 of this form if you have questions about the study procedures or payment, or if you get hurt or become sick during the study.

The Capella Research Integrity Office (RIO) has been established to protect the rights and welfare of human research participants. Please contact us at 1-888-227-3552, extension 4716, for any of the following reasons:

- You have questions about your rights as a research participant.
- You wish to discuss problems or concerns.
- You have suggestions to improve the participant experience.
- You do not feel comfortable talking with the researcher.

You may contact the RIO without giving your name. We may need to reveal information you provide to be able to follow up if you report a problem or concern.

**DO YOU WANT TO BE IN THIS STUDY?**

I have read this form, and I have been able to ask questions about this study. The researcher has talked with me about this study. The researcher has answered all of my questions. I voluntarily agree to be in this study. I agree to allow the use and sharing of my study-related records as described above.

By signing this form, I have not given up any of my legal rights as a research participant. I will get a signed copy of this consent form for my records.

______________________________
Printed Name of Participant

______________________________  _______________________
Signature of Participant          Date

I attest that the participant named above had enough time to consider this information, had an opportunity to ask questions, and voluntarily agreed to be in this study.

______________________________
Printed Name of Researcher
DO YOU WISH TO BE AUDIOTAPED IN THIS STUDY?

I voluntarily agree to let the researcher audiotape me for this study. I agree to allow the use of my recordings as described in this form.

Printed Name of Participant

Signature of Participant       Date

Capella IRB Approval

Approved for 1 year after this date: 6.10.2013