

## **Dissertation Title, Lead Question, and Guiding Questions**

### ***Research Title:***

High school educated parents lived experience homeschooling children with autism: A phenomenology study.

### ***Leading Question:***

What is your lived experience, as a high school educated parent, homeschooling a child with Autism Spectrum Disorder (ASD)?

### ***Guiding Questions:***

1. What does your school day consist of?
2. Can you explain what your emotional wellbeing is like educating a child with ASD??
3. What was the experience like for you deciding to homeschool your child with ASD?
4. Do you feel capable and or equip to educate your child with ASD?
5. Are there concerns you have about your educational level when homeschooling your child with ASD?
6. How has educating your child with ASD impacted your family's daily life?
7. Are there things you would have done differently, knowing what you know now about homeschooling a child with ASD?
8. What other input or insights can you share about your daily lived experience with homeschooling your child with ASD?

Date: September 7, 2016

From: The Institutional Review Board (IRB)

Re: 2016-1051

Study title: High school educated parents lived experience homeschooling children with autism: A phenomenology study.

Submission type: Initial Submission

Review level: Expedited

Dear Kevin Harrison,

On behalf of Capella University's Institutional Review Board (IRB), we are writing to inform you that your study has been approved. All research must be conducted in accordance with this approved submission, meaning that you will follow the research plan you have outlined here, use approved materials, and follow university policies.

Please take special note of the following important aspects of your approval:

- Most programs have additional milestone requirements before data collection may proceed. You must complete those milestones before collecting data.
- Any changes made to your study require approval from the IRB Office before they can be implemented as part of your study. Contact the IRB Office at **irb@capella.edu** with your questions and/or proposed modifications.
- Based on the risks involved, this project requires continuing review every **12 months**. Approval of this research will remain in effect until **September 6, 2017**.
- Continuing review is required as long as you are in data collection or data analysis. If you do not receive continuing review approval by the expiration date **you must cease all study activities at the time of approval expiration**.
- You must use the approved informed consent form
- If there are any unanticipated problems or complaints from participants during your data collection, you must notify the Capella IRB Office **within 24 hours of the data collection problem or complaint**.
- Monitoring of the consent process or data collection and analysis may occur. The IRB will notify you if your study will be audited.
- Per the [Doctoral Learner policy](#), you are required to be enrolled during recruitment, data collection, and data analysis. If you are not enrolled, you must cease recruitment, data collection and analysis.

The Capella University IRB is pleased to congratulate you on achieving this milestone. Best wishes as you conduct your research!

Regards,

**Capella University Institutional Review Board**

Email: [irb@capella.edu](mailto:irb@capella.edu)



## INFORMED CONSENT FORM

**Study Title:** High school educated parents lived experience homeschooling children with autism: A phenomenology study

**Researcher:** Kevin Harrison

**Email Address and:** kharrison4@capellauniversity.edu

**Telephone Number:** 1 (606) 922-2391

**Research Supervisor:** Dr. Kim Kostere

**Email Address:** Kim.Kostere@capella.edu

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

If you have any questions 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.

### WHAT IS THIS STUDY ABOUT?

The researcher wants to learn about? The purpose of the study is to understand the experiences of mothers that have a high school diploma and homeschool their child/children with Autism Spectrum Disorder (ASD). In order to give behavioral, health care, social workers, educators and consultants a better understanding of what parents experience and how to better meet their needs.

The researcher also wants to know how parents with high school diplomas, experience the educational process raising their child with autism and insights they can add to assist that may assist other parents struggling with making the decision to homeschool their child or children with autism.

### WHY AM I BEING ASKED TO BE IN THE STUDY?

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

- **You are a parents who homeschool and have a high school diploma or GED**
- **One or more of your children have been diagnosed with ASD**
- **You homeschool your child or children with ASD**

All participants must be a minimum 18 years old or above at the time of the study in order to be involved in the research.

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 8-10 participants will be in this study.

### **WHO IS PAYING FOR THIS STUDY?**

The researcher is not receiving funds to conduct this study and is paying for any incurred expenses.

The researcher is a PHD candidate at [Capella University], but is not receiving funds to conduct this study. The researcher will not be paid for conducting the study. [The researcher is a part of the homeschooling community but does not have any children with Autism Spectrum Disorder]

### **WILL IT COST ANYTHING TO BE IN THIS STUDY?**

There will be no cost to any participants in the study.

### **HOW LONG WILL I BE IN THE STUDY?**

If you decide to be in this study, your participation will last about **45 minutes to an hour for an interview and follow-up questions may be necessary but can be done over the phone or via email**. You will have to come to a location convenient for you one time for an interview during the study.

### **WHAT WILL HAPPEN DURING THIS STUDY?**

If you decide to be in this study and if you sign this form, you will do the following things:

- Give personal information about yourself, such as **[full name, address, contact information, educational level, ethnicity, socio-economic status, pay scale range, and information about your homeschooling experience with your child or children with ASD]**.
- Answer questions during an interview and follow up questions about **[your experience homeschooling your child or children with ASD]**.
- Allow a researcher to look at or explain your homeschooling records and educational materials used.

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 entire **interview session**. The researcher will use the audiotape in order to **[transcribe your experience exactly as stated by you to give a clear and precise picture of homeschooling your child or children with ASD. This information will then be analyzed with other participants feedback to build a consensus to help formulate a better understanding of homeschooling children with ASD]**

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

### **WILL BEING IN THIS STUDY HELP ME?**

Being in this study will not help you. Information from this study might help researchers help others in the future. The information will be used to help other professionals better understand the experience of parents who homeschool their children with ASD.

### **ARE THERE RISKS TO ME IF I AM IN THIS STUDY?**

No study is completely risk-free. However, we don't 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. If when answering some of the questions during the interviewing process you may have some discomfort in discussing your interactions with your child or children during your daily educational interactions with them, please inform the researcher and the interview will end. Please remember, you will always have the right to stop or proceed as you feel comfortable sharing your experiences.

### **WILL I GET PAID?**

If you participate, you will not receive any payment for your participation.

### **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 discontinue your participation 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 about 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. Once you decide to participate in the study your demographic information will be taken by the researcher. The researcher will then assign you an alias or fictitious name in order to protect your true identity. You will keep this name to identify you throughout the study. Only the researcher, the researcher's mentor and other necessary university officials will have access to this information. Information will be kept on an encrypted flash drive and stored in a safe or safety deposit box. Only your alias will appear in any written reports or publications, no one will be able to identify you.

The researcher will keep the information you provide in a safe, where all research information will be stored. Electronic information will be kept in the same location and will also be on an encrypted flash drive. All research documents will be kept in the safe at the researcher's residence and only the researcher, researcher's supervisor, and dissertation committee will have access to your study data. Additionally, Capella University's IRB, the Research Compliance Committee (RCC), or its designees may review your research records.

[All interviews will be recorded and only the researcher, researcher's supervisor, and dissertation committee will have access to your study data. Additionally, Capella University's IRB, the Research Compliance Committee (RCC), or its designees may review your research records. Additionally a transcriptionist may be employed to transcribe the information from the recordings to written form. The transcriptionist will not have access to any identifying data of the participants and will also have to sign a confidentiality agreement. After the information is transcribed the transcriptionist will no longer have access to the research information.]

Even if you leave the study early, the researcher may still be able to use your data. **[If you decide to leave the study, there may be enough valuable information for the researcher to use in order to answer some of the questions important to the research. If this is the case, the information can be used to help complete the study. If you decide to leave the study for any reason and do not wish your information to be used, you can make a request to the researcher who will remove your information and dispose of it.]**

### **Limits of Privacy (Confidentiality)**

Generally speaking, the researcher can assure you that she/he will keep everything you tell him/her or do for the study private. Yet there are times where the researcher cannot keep things private (confidential). The researcher cannot keep things private (confidential) when:

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

There are laws that require many professionals to take action if they think a person is at risk for self-harm or are self-harming, harming another or if a child or adult is being abused. In addition, there are guidelines that researchers must follow to make sure all people are treated with respect and kept safe. In most states, there is a government agency that must be told if someone is being abused or plans to self-harm or harm another person. Please ask any questions you may have about this issue before agreeing to be in the study. It is important that you do not feel betrayed if it turns out 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, study costs (if any), study payment (if any), or if you get hurt or sick during the study.

Capella University's Institutional Review Board (IRB) has been established to protect the rights and welfare of human research participants. Please contact us at 1-888-227-3552, extension 6313, 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 IRB without giving us your name. We may need to reveal information you provide in order 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 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.

Kevin Harrison  
\_\_\_\_\_  
Printed Name of Researcher

\_\_\_\_\_  
Signature of Researcher

\_\_\_\_\_  
Date

**DO YOU WISH TO BE AUDIOTAPED IN THIS STUDY?**

Yes  No 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.

**ARE YOU WILLING TO BE CONTACTED BY EMAIL OR PHONE IN THIS STUDY?**

Yes  No I agree to allow the researcher to contact me by email

yes  No I agree to allow the researcher to contact me by phone

\_\_\_\_\_  
Printed Name of Participant

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date