**Informed Consent for Participation in a Research Study**

IRB # **NCR202777**: Making Work Work: Self-Determination Behaviors and Quality Employment for Adults with Autism

Principal Investigator: Dr. Elisabeth Rice, Associate Professor, [***ehess@gwu.edu***](mailto:ehess@gwu.edu), 202-994-1535 (GSEHD)

You are invited to participate in a research study under the direction of Dr. Elisabeth Rice in Department of Special Education and Disability Studies in The Graduate School of Education and Human Development, at The George Washington University (GWU). Taking part in this research is entirely voluntary. Further information regarding this study may be obtained by contacting Dr. Elisabeth Rice, Associate Professor, [ehess@gwu.edu](mailto:ehess@gwu.edu), at telephone number (202) 549-3222.

My doctoral student, Adam Berman, and I are conducting a study to explore how self-determination affects the employment of adults with autism and the quality of employment. The purpose of this study is to gain a greater understanding of how teaching self-determination and practicing self-determination impacts employment for adults with autism. We are interested in interviewing and surveying adults with autism who meet the following criteria: (1) are employed or ever have been employed and (2) are 18 years or older.

There will be a electronic survey that will take 15-30 minutes to complete and one interview lasting 30 to 45 minutes in length. After completion of the survey, you will be placed into a drawing to receive a $25 gift card. After the completion of the interview, you will receive a $10 gift card to thank you for your time. There may also be one follow-up phone conversation lasting no more 10 - 20 minutes. Your identity and recorded data will be kept private and confidential throughout the study, and no identifying information will be shared.

The purpose of this study is to gain a greater understanding of how teaching self-determination and practicing self-determination impacts employment for adults with autism. In this study:

* Whether or not you take part is up to you.
* You can choose not to take part.
* You can agree to take part and later change your mind.
* Your decision will not be held against you.
* You can ask all the questions you want before you decide.

You are being asked to take part in a research study about your employment experiences as an adult with autism. Your participation is completely voluntary. You have been found eligible for this study because you meet the following criteria: (1) You are currently employed or have been employed in the past and (2) You are over the age of 18.

This page will give you key information to help you decide whether or not you want to participate in this study. More detailed information can be found on the next pages.

If you have any questions please ask the research team during the consent process and use the contact information on this form to ask questions later.

*What are the reasons you might choose to volunteer for this study?*

We cannot promise any benefits to you from your taking part in this research. However, possible benefits include the opportunity to share your story and experience to interested researchers. There is no benefit outside of this sharing of experiences.

*What are the reasons you might not choose to volunteer for this study?*

The risks and discomforts associated with participation in this study are not expected to be greater than those ordinarily encountered in daily life or during the performance or routine physical or psychological examinations or tests. There are no physical risks associated with the study, but there is a risk of loss of confidentiality or privacy of the subjects. There are multiple procedures in place to de-identify your information and protect against any loss of confidentiality (*see “What happens to my information collected for the research?’ section below).*

There is some psychological risk in being asked to share personal information. Possible risks or discomforts you could experience during this study include: discomfort in responding to interview questions or possible distress related to personal questions being asked.

*What will happen if I agree to be in this research study?*

If you choose to take part in this study, a mutually agreed upon date, time, and location will be determined for one individual interview via Zoom or Webex.

The total amount of time you will spend in this study is approximately 75 minutes. A short phone call, lasting approximately 10-20 minutes, will be made approximately two- four weeks after your interview for any additional follow-up.

At any time, you may choose to end your participation.

* 1. Upon agreement to participate in this study, via email or a phone conversation, a date, time, and location will be determined that is mutually agreeable. A confirmation email will also be sent to you with this information.
  2. At the mutually agreed upon date and time you will be assigned a fictional name which will be used for the interview.
  3. The interview will consist of semi-structured questions. At any time, you may choose to end your participation. The interview will be recorded by a digital audio recording device and the video conferencing software. The interview will be transcribed immediately after the interview. After the interview has been transcribed you will be contacted via email to see if you would like to see the transcripts.
  4. Approximately two -four weeks after your interview, you will be sent an email asking if you would agree to a short follow-up phone conversation to offer any additional sharing of experiences.

Possible risks or discomforts you could experience during this study include: a risk of loss of confidentiality or privacy of the subjects. There is also a minimal risk of strong feelings associated with recounting distressing experiences.

There are no physical risks associated with this study.

You will not benefit directly from your participation in the study. The benefits to science and humankind that might result from this study are that educators, policy makers, other adults with autism, and parents will learn about the experiences about gaining and keeping employment as an adult with autism. Through learning about the employment experiences of adults with autism, new information and perspective will be gained for educators, families, and policy makers to advocate for programs, interventions, and actions to improve employment outcomes for people with autism.

Every effort will be made to keep your information confidential, however, this cannot be guaranteed. If results of this research study are reported in journals or at scientific meetings, the people who participated in this study will not be named or identified. Your identity and recorded data from the interview will be kept private and confidential throughout the study and no identifying information will be shared. We cannot promise complete secrecy. Email address will be linked to the data, since we will email you a copy of the transcript for accuracy and verification. Aside from this, all personally identifiable information will be confidential and will be stored separately from the data at all times and is only accessible to the research team.

All such correspondences will be destroyed after the completion of this study. The IRB and other representative of this organization may inspect and copy your information. Please be informed that the following steps are taken to protect your identity.

1. Each participant will be assigned a fictional name, which will be used for interview transcriptions as opposed to including real participant and dependent names with the interview data.
2. Each participant’s interview data will also be assigned a number code that is randomly generated to assist with the organization of data and also protection of confidentiality.
3. The interview will be recorded by a digital audio recording device and then transcribed into written form. The digital audio recordings of the interviews will be stored in a locked drawer on location with members of the research team until the manual transcription is complete. Once the transcripts are completed in May 2021, the digital audio recordings will be destroyed. The video of the interview will be analyzed after the interview and destroyed following a review on May 2021.
4. The computer files will be stored on password protected computers only available to the research team. The files will not have the participants’ names. The research team will have a list that matches the randomly assigned number with the assigned fictional name and contact information given by the participant (i.e., phone number or email address). The list with personally identifiable information will be kept separate from the data. The computer files will be destroyed upon the completion of the study in August 2021. All email communications will be stored on password-protected computers in a password-protected email system for the duration of the study. All email correspondence will be destroyed upon completion of the study in August 2021.
5. The research team will not release any information about the participants’ involvement without written permission from the participant, unless required by law.
6. All email contacts, participant contact information, and data sets will be destroyed upon completion of the study in August 2021.

The Office of Human Research of George Washington University, at telephone number (202) 994-2715, can provide further information about your rights as a research participant.

Your willingness to participate in this research study is obtained through completion of the electronic survey and verbal consent prior to the interview.

\*Please keep a copy of this document in case you want to read it again.

