

**University of Alabama
Intellectual Disabilities Participant Registry**

Department of Psychology
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REGISTRY ENROLLMENT INFORMED CONSENT FORM: STANDARD VERSION

You and your child are invited to enroll in a research participant registry. This registry is called the "University of Alabama Intellectual Disabilities Participant Registry." The registry is being developed by Dr. Frances Conners, a professor at the University of Alabama. If you need help completing this form, please contact the Registry Coordinator at 205-348-4253 or idlab@ua.edu.

WHAT IS THE REGISTRY FOR?

The purpose of this registry is to help researchers locate research participants for their studies on intellectual disability (formerly called mental retardation). Families add their information to the registry and researchers use the registry to locate participants who are good matches for their studies. This registry gives families a chance to actively support research on intellectual disability. All studies that use the registry must be *not-for-profit* and *minimal risk* for participants. We hope to enroll 500 families in this registry.

WHAT WILL OUR PARTICIPATION IN THE REGISTRY INVOLVE?

If you decide to enroll in the registry, you will be asked to do the following things: (1) To enter the registry you will complete this consent form and the *Abbreviated Background Questionnaire* and return them to the Registry Coordinator. This will take about a half hour. (2) When there is a study that your family matches, the Registry Coordinator will contact you to see if you are interested in participating in that study. If you are interested in participating, the Registry will give your contact information to the study personnel. (3) Twice a year, the Registry Coordinator will contact you to update your information.

WHAT INFORMATION WILL BE KEPT IN THE REGISTRY?

The following information from the *Abbreviated Background Questionnaire* will be recorded in the participant registry: (1) Information about the child/family member with intellectual disability--name, birth date, sex, race, hearing, vision, speech/language, diagnoses, and birth history. (2) Information about the parents/family--names, addresses, telephone numbers, email addresses, family income level, mother's education, number and ages of children. (3) After your family is matched to a study, we will add the name of the study you were matched to and the date. (4) When participating in a research study, we may ask you for permission to add other information to the registry. This may include standardized test scores, vision, and hearing. This information will make it easier to match families with studies in the future. It will be your free choice whether to add this information to the registry, and we will always ask your permission first.

ARE THERE ANY RISKS OR BENEFITS TO ME OR MY FAMILY?

There are no foreseeable risks or direct benefits to you or your family.

Please initial _____

WILL WE BE COMPENSATED FOR OUR TIME AND EFFORT?

No, you will not be compensated.

UNIVERSITY OF ALABAMA IRB
CONSENT FORM APPROVED: 3/10/17
EXPIRATION DATE: 3/9/2018

HOW WILL OUR CONFIDENTIALITY (PRIVACY) BE PROTECTED?

Information about your family will be kept confidential. In other words, we will not give the information to anyone outside of the registry without your permission. We will keep your information in a password-protected secure computer database with your names and contact information separated from your other information. If your information was originally on paper, we will keep these papers in a locked file cabinet for one year, when they will be destroyed.

WHOM SHOULD I CONTACT IF I HAVE QUESTIONS?

If you have questions about the participant registry right now or later on, please call the Registry Coordinator at 205-348-4253 or Dr. Frances Conners at 205-348-7913. If you have questions about your rights as a person taking part in a research study, wish to make suggestions or file complaints and concerns, you may call Ms. Tanta Myles, the Research Compliance Officer of the University at (205)-348-8461 or toll-free at 1-877-820-3066. You may also ask questions, make suggestions, or file complaints and concerns through the IRB Outreach Website at http://osp.ua.edu/site/PRCO_Welcome.html. You may email us at participantoutreach@bama.ua.edu.

WHAT ARE OUR RIGHTS AS RESEARCH PARTICIPANTS?

Taking part in this registry is voluntary—it is your free choice. Enrolling in the registry does not mean that you must participate in a research study when invited. Each time you are invited to participate in a research study it is your free choice about whether to participate in that specific study. Also, it is your free choice to withdraw from the registry at any time (to do so, please contact the Registry Coordinator at Box 870348 Tuscaloosa, AL 35487-0348 or 205-348-4253 or ldlab@ua.edu). If you withdraw from the registry we will no longer contact you to participate in research studies. Withdrawing from the registry will not result in any negative consequences to you.

Please sign below that you understand the information in this consent form, you have had a chance to ask questions, and you freely agree for your family to participate in the registry. If your child with intellectual disability is of majority age in your state, he/she should sign his/her own agreement to participate after discussing the registry with you. You will receive a copy of this consent form to keep.

Name of Parent/Guardian (please print)

Signature of Parent/Guardian

Date

Name of Child (please print)

Signature of Adult Child (required if 18 years old or older in AL, GA, or FL, or 21 years old or older in MS)

Date

Signature of Registry Coordinator

Date

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