

**University of Alabama  
Intellectual Disabilities Participant Registry**

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**REGISTRY ENROLLMENT INFORMED CONSENT FORM: ADULT VERSION**

\*For use when person with ID is a legal adult (at least 18 in GA, FL, and AL, or 21 in MS)  
and either legally independent or has a court appointed guardian\*

You are invited to join a research participant registry. This registry is called the "University of Alabama Intellectual Disabilities Participant Registry," and it is run by Dr. Frances Connors, a professor at the University of Alabama. If you need help with this form, please call 205-348-4253 or email idlab@ua.edu.

**WHAT IS THE REGISTRY FOR?**

The registry is a way for people with intellectual disabilities to help researchers learn about intellectual disability by being a research participant. A research participant is someone who answers questions or does tasks in a research study. If you join the registry, we will call you when there is a research study you can help with. All studies that use the registry are *not-for-profit* and *minimal risk* for participants. We hope to have 500 people join the registry.

**WHAT WILL I DO IF I JOIN THE REGISTRY?**

If you join the registry, you will sign this consent form and fill out the *Abbreviated Background Questionnaire*. This will take about a half hour. When there is a study you can help with, the Registry Coordinator will call you and tell you about it. If you decide to help with that study, the Registry Coordinator will give your phone number to the researcher and the researcher will call you. Also, the Registry Coordinator will call you 2 times a year to find out if your address or phone number has changed.

**WHAT INFORMATION WILL BE KEPT IN THE REGISTRY?**

Information from the *Abbreviated Background Questionnaire* will be kept in the registry. This includes your name, birth date, sex, race, and other things about you. It includes your parents' or guardians names, addresses, telephone numbers, and other things about them. If we call you to help with a study we will put the name of the study in the registry and the date we called you. When you help with a research study, we will ask you if we can add your test scores, vision scores, and hearing scores. It will be your free choice to add these scores to the registry, and we will always ask you first.

Please initial \_\_\_\_\_

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EXPIRATION DATE: 3/9/2018

**ARE THERE ANY RISKS OR BENEFITS TO ME?**

There are no special risks or direct benefits to you.

**WILL I BE COMPENSATED FOR MY TIME AND EFFORT?**

No, you will not be compensated.

**HOW WILL MY CONFIDENTIALITY (PRIVACY) BE PROTECTED?**

We will not give information about you or your family to anyone outside of the registry without asking you first. We will keep your information in a password-protected computer file with your name separated from your other information. If your information is on paper, we will keep these papers in a locked file cabinet for one year, and then they will be destroyed.

**WHOM SHOULD I CALL IF I HAVE QUESTIONS?**

If you have questions about joining the registry, please call the Registry Coordinator at 205-348-4253 or Dr. Frances Connors 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](http://osp.ua.edu/site/PRCO_Welcome.html). You may email us at [participantoutreach@bama.ua.edu](mailto:participantoutreach@bama.ua.edu).

**WHAT ARE MY RIGHTS AS A RESEARCH PARTICIPANT?**

Joining the registry is voluntary—it is your free choice. Joining the registry does not mean that you must help with a research study when asked. Each time you are asked to help in a research study it is your free choice. Also, it is your free choice to take yourself out of the registry at any time. Just call the registry at 205-348-4253 or email [idlab@ua.edu](mailto:idlab@ua.edu). If you take yourself out of the registry we will no longer call you to help with research studies and nothing bad will happen.

Please initial \_\_\_\_\_

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**Please sign below** that you understand the information in this consent form, you have had a chance to ask questions, and you freely agree to participate in the registry. You will have a copy of this consent form to keep.

\_\_\_\_\_  
Name of Participant (please print)

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

\_\_\_\_\_  
Date

- **If you have a Court Appointed Guardian**, please also have that person sign below, consenting to your participation:

\_\_\_\_\_  
Name of Court Appointed Guardian (please print)

\_\_\_\_\_  
Signature of Court Appointed Guardian

\_\_\_\_\_  
Date

- **If you DO NOT have a Court Appointed Guardian**, please have some other person (such as a family member, a supervisor, a caseworker, etc.) sign below as a witness that you understand the information in this consent form, you have had a chance to ask questions, and you freely agree to participate in the registry:

\_\_\_\_\_  
Name of Witness

\_\_\_\_\_  
Relationship to Participant

\_\_\_\_\_  
Signature of Witness

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Registry Coordinator

\_\_\_\_\_  
Date

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