

## Registry Use Agreement – Clean version

### University of Alabama Intellectual Disabilities Participant Registry

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#### REGISTRY USE AGREEMENT

The University of Alabama Intellectual Disabilities Participant Registry maintains contact information of families with a member with intellectual disability. These families have agreed to be contacted to participate in research studies. An important goal of the registry is to promote a greater quantity and quality of research on intellectual disability in the southeastern states. Thus, researchers in Alabama, Georgia, and Mississippi, as well as in other states, may request access to research participants through the registry.

#### Registry Principles

- The primary purpose of the registry is to provide a system for contacting potential participants to invite them to participate in scientific research studies.
- The registry operates under IRB approval and participation in the registry is voluntary.
- The registry is available to other researchers for scientific research on intellectual disability.
- The registry data are stored in a secure system and accessed only by designated personnel.
- The operation and use of the registry is monitored quarterly by Dr. Frances Connors, the Principal Investigator for the registry.

#### Procedure for Accessing Research Participants

1. Initial contact with Registry Staff. Researchers interested in utilizing the services of the Registry as a recruitment avenue for a specific study should first speak with the Registry Staff about the study attributes (e.g., number of participants needed, diagnosis, eligibility criteria, etc.).
2. Initial Registry search. Registry Staff will then conduct a *no cost search* of the Registry to determine the number of Registry participants who potentially could participate in the researcher's study. Based on the number of potential participants gathered from the search, the researcher may then decide whether or not proceed to the next phase.
3. Registry Use Agreement. If the researcher would like the Registry to contact potential participants for his/her study, s/he will complete the Registry Use Agreement. Also, the researcher will submit an IRB-approved plan for scientific research that is *not-for-profit* and *minimal risk* for participants. This plan should include the number and types of participants desired for the project, a lay description of the project, copies of the required consent form(s), and a copy of the IRB approval document.
4. Contact of potential participants. Once the Registry Use Agreement and the required documentation are received and the request is approved by the Registry, the researcher's account will be opened for one month. During this period, Registry Staff will work on identifying participants for the research study. This will include contacting potential participants, describing the study to them, reviewing the informed consent document, and determining if they are willing to be contacted by the researcher and if there is any interest in participation.

At the end of the month, Registry Staff will provide the researcher with the contact information for the Registry participants who expressed interest in study participation and consented to being contacted by the researcher. At this time,

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

fees for sustaining the Registry must be paid by the researcher (see below for information on fees). Once the participant contact information is exchanged and fees are paid, the researcher will have the option to renew their account with the Registry, or close it out. Renewal of the account simply means that the Registry Staff will continue to contact additional participants for your research study, with commensurate fees required.

Note on yield and reimbursement to the Registry. Researchers should understand that each participant identified in the initial search is free to choose to participate or not to participate in the researcher's study. Thus, the number of participants referred to the researcher may be substantially less than the number of participants identified in the initial search. Also, a participant's agreement to be referred to the researcher does not constitute agreement to enroll in the researcher's study. Thus, the number of participants enrolled in the researcher's study may be less than the number of participants referred to the researcher. The Registry requires reimbursement based on the number of participants referred to the researcher.

### **Registry Use Requirements**

Researchers using the participant registry must agree to the following:

1. Contact every participant identified for your study.
2. Complete testing within 6 months of when participants were identified for your study.
3. Consider requesting permission from your IRB to add certain data from your study to the registry database using the Data Transfer and Update Informed Consent Form (e.g., date of participation, standardized test scores, vision and hearing data). If you would like to do this, the Registry will provide you a Data Transfer Authorization Form from the Registry. The Registry will use this information to match participants to studies in the future, so this will help the Registry function better for researchers.
4. Provide an update of study findings (in lay terms) each year in which participants are identified for you by the registry. These reports will be used to keep registry participants informed about the research using the registry.
5. Do not contact the same families outside of the registry that have been identified for you by the registry (i.e., for a second study). This could result in too many requests going out to certain families. Instead, go through the registry again. The registry will keep track of the number and timing of research requests to specific families to avoid overburdening them.
6. Consider referring new families to the registry when possible. This will help us keep the registry growing.
7. Pay a registry fee to support the continued operation of the registry. The fee for the trial period is \$10 per participant referred (i.e., with contact information). This payment is required at the time participant contact information is given to the researcher.

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

I understand the requirements of the University of Alabama Intellectual Disabilities Participant Registry as described above and I agree to comply with them.

\_\_\_\_\_  
Researcher's Name

\_\_\_\_\_  
Date

\_\_\_\_\_  
Researcher's Signature

\_\_\_\_\_  
Email Address

\_\_\_\_\_  
Phone Number

\_\_\_\_\_  
Mailing Address

\_\_\_\_\_

\_\_\_\_\_  
Name of Study

Submission Checklist:

- Research Description (not more than one page)
- Description of number and types of participants desired
- Copy of consent form to be used
- Copy of IRB approval document