

UAIDPR Newsletter

Spring 2022

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THE UNIVERSITY OF
ALABAMA

College of
Arts & Sciences
Intellectual Disabilities Participant Registry

What is the UAPDR? The University of Alabama Intellectual Disability Participant Registry (AKA "The Registry") is a database of families and individuals with intellectual disability (ID) who are interested in participating in behavioral research studies.

Facts about the UAIDPR

Who can join the registry?

Anyone with an intellectual disability with any cause who is interested in participating in research studies may join the registry. We accept all ages and participation in the registry is completely voluntary, you may withdraw at any time.

What are the research studies like?

The registry supports studies on intellectual disability (ID) that focus primarily on behavior (e.g., learning, cognition, social skills), pose minimal risk to participants, and are approved by their institution for ethical treatment of participants. Beyond these principles, we do not restrict studies by research concept and we welcome any study that hopes to improve the lives of those with ID.

If my family joins the registry, how would we be contacted about study participation?

When you join the registry, you will provide your contact information as well as basic demographic information. When there is a study that might fit, the registry will contact you to see if you are interested. If your contact information has changed, please let us know by emailing idl原因@ua.edu. We also try to contact our registry families every 6 months to confirm and update contact information.

Why haven't I been contacted yet?

Many of the current studies we are supporting focus on young adults and children. We hope researchers looking at different age groups will reach out to us for recruitment support.

How can I contact the registry?

- Email idl原因@ua.edu
- Call 205-348-4253
- Website uaidpr.ua.edu

Featured Study

Quick Facts!

- ∅ This study is done fully over ZOOM
- ∅ This study is being done by The University of Alabama in collaboration with Montclair University located in New Jersey
- ∅ Looking for individuals with Down Syndrome 10 – 25 years old
- ∅ Looking for typically developing children 4 – 9 years old

If interested in participating please contact idl原因@ua.edu or call 205-348-4253

Improving Spatial Skills in Youth with and without Intellectual Disabilities

We all use spatial abilities every day without even thinking about it. Spatial abilities help us understand and remember the relations among objects and the relation of ourselves to objects. For example, if I want my cup of coffee, I need to know where I put it, how far away it is from me, where exactly the handle is, etc., so I can successfully reach it and hold it to drink some coffee. Most of us will acquire spatial skills naturally through experience, but some of us struggle with spatial skills. Our research has shown that some spatial skills are especially difficult for many individuals with Down syndrome.

Purpose of the Study

This study asks, “Can spatial skills be improved with practice in young people with Down syndrome?” and “What types of practice foster improvement?” The study focuses on two important but difficult spatial skills: mental rotation and perspective taking. Mental rotation is the ability to picture an object and mentally turn it different angles. This skill is used in situations like packing a grocery bag, one must picture the object about to be packed and the best orientation for the object to be placed in the bag. Perspective taking is the ability to imagine looking at an object from a different position, for example, from behind it. This skill may be used when trying to find a lost item or a new path to a destination.

Participant Activities

The study typically takes about 4 ½ months to complete. It includes initial assessment of spatial skills (two 1-hour sessions), 16 weeks of extended practice on the computer (spatial games such as puzzles, building blocks, and virtual search tasks), and follow-up assessment. The length of extended practice is needed to allow the effects to begin to work. It is possible to take breaks in testing (e.g., taking 1 – 2 weeks off for holidays and vacations) which may increase overall length of the study. It is also possible to adjust the number of practice sessions per week or length of the sessions to fit participants’ schedules and potentially reduce total time in the study.

Study Spotlights

Cognitive Changes



Funded by the
National Institutes of
Health!



Reading Skills



Funded by the
National Institutes of
Health!

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Cognitive Changes in Teens and Young Adults

This study is by Dr. Conners at UA and Dr. Abbeduto at UC Davis. It seems that people with intellectual disabilities (ID), especially Down syndrome (DS), may experience age-related decline earlier than the general population. This study will look at patterns of change over time. It aims to identify early signs of cognitive aging in memory, language, and everyday skills.

- Who? Recruiting individuals with DS or ID ages 15-25 years old and their caregivers
- When? We are ACTIVELY recruiting for this study!
- Where? At our lab at UA or a location of your choice
- What to expect? Participants will complete cognitive tasks using picture books and iPads over 2-3 sessions. Caregivers will complete an interview and measures using an iPad. We will do this three times at 18 month intervals over 3 years. As a thank you, participants will get a gift card each time.

Reading Skills in Children and Teens

This study is by Dr. Loveall at the University of Nebraska and Dr. Conners at UA. Often, youth with Down syndrome (DS) or intellectual disability (ID) do well with word reading but struggle with reading comprehension. This study aims to better understand why youth with DS or ID sometimes struggle with reading comprehension.

- Who? Recruiting individuals with DS or ID ages 10-15 years old and typically developing kids ages 6-10 years old
- When? We are ACTIVELY recruiting for this study!
- Where? At our lab at UA or a location of your choice
- What to expect? Participants will complete cognitive tasks using pictures, books and iPads in two interactive testing sessions. Participants will receive a \$40 gift card as a thank you!



Want to participate in any of these studies?

Email: idl原因@ua.edu

Call: (205) 348-4253



Study Spotlights

Project Pathways



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Project Pathways

This study is by Dr. Susan Loveall and Dr. Derek Rodgers at the University of Nebraska Lincoln. The purpose of this study is to assess the reading and writing profiles of students with intellectual and developmental disabilities.

- Who? Recruiting individuals who are middle or high school students (ages 13-21 years) with intellectual and developmental disabilities and must be fluent in English and have internet access to participate.
- When? We are ACTIVELY recruiting for this study!
- Where? At your home and over Zoom! This study is completely online!
- What to expect? Participants will spend two hours completing a variety of assessments that target reading and writing skills of students with intellectual and developmental disabilities. Participants will receive a \$20 gift card for completing the study.

Early Cognitive Decline: Pilot Study Update

A few years ago, we recruited many registry families to participate in one of our studies, the Early Cognitive Decline Pilot Study. The data from this pilot study allowed us to get federal funding for a much larger study (see p. 3). Also, this year, our registry coordinator, Chelsea Chen, (with the help of Dr. Gayle Fought, Dr. Fran Connors and Kristina Baggett) presented some findings from the pilot study at the Down Syndrome Research Forum and the Cognitive Development Society Conference.

Chelsea reported that community skills such as using the telephone, achieving goals, using technology, and eating out at restaurants seem influenced by how much experience individuals with Down syndrome have with each given situation and also how well their memory functions. This suggests that community skills encompass a wide range of functionality and depend on both cognitive functions and environmental factors for acquisition.

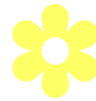
TAKE-HOME MESSAGE: If you want to build your community skills, spend more time engaged in community activities. Also, tend to memory issues – if forgetting happens often, consider adding memory supports like checklists or labels.

We want to say THANK YOU to all the families who participated in this pilot study, as these findings would not have been possible without you!

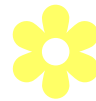
Get to Know the Research Assistants



My name is Lauren Herrin and I work on Dr. Fran Connors' *Reading Skills* study as a research assistant and examiner. I am in charge of scheduling participants, administering assessments, and training new lab members. I also serve as the main point of contact for the parents who are interested in having their child participate in our study. A fun fact about me is that I'm a Tuscaloosa native.



My name is Kate Duffley, and I am Junior working as a research assistant on the *Reading Skills* study. I mainly work on assessment session 1 of the study, but you also might see me at assessment session 2. I do the hearing and vision, Leiter, and Woodcock Reading assessments. A fun fact about me is that I am studying abroad in Italy this summer! I am looking forward to working with you on the study!



My name is Sarah Amjad, and I am an undergraduate research assistant in the *Cognitive Changes* study. I am excited to be administering the Vineland interview to caregivers in this study. I am a biology major and a psychology minor on the pre-medical track. Excited to meet you!



My name is Catherine Stodola and I work on the *Reading Skills* study as a student examiner. I might be in charge of any of the assessments for either session 1 or session 2 of testing. A fun fact about me is that I love playing board and card games with my friends and family.



My name is Alauna Reckley and I am currently working on the *Cognitive Change* study as a graduate student research assistant. I will mainly be in charge of the parent measures. One fun fact about me is that I am left-handed, along with both of my sisters, while my mother once was ambidextrous but is not right-handed.

Upcoming Events and News

Upcoming Fundraisers

**Down Syndrome Alabama
Tee Up for Down Syndrome**
June 20th, 2022, Inverness
Country Club, Birmingham, AL

<https://downsyndromealabama.org/tee-up-for-down-syndrome/>

**The Arc of Shelby County
Swinging Fore Achievement
Golf Tournament**
May 19th, 2022, Ballantrae
Golf Club, Pelham, AL

<http://thearcofshelby.org/events/swinging-fore-achievement-golf-tournament/>

Unless U
Unless U Got Talent
May 14th, 2022, The Lyric
Theater in Birmingham, AL

<https://www.unlessu.org/uugottalent>



Participant Spotlight



Pictured here is one of the participants in our study posing with Dr. Gayle Faught and Research Assistant Chelsea Chen! Thank you so much for taking the time to be a part of our study. We hope to keep working with you in the future!

*Like our Facebook
Page!*



Facebook.com/UAIDPR

Thank you!

To all our supporters and registry participants – we appreciate your help in promoting our registry and research on intellectual disability.

Get in Touch!

**University of Alabama Intellectual
Disabilities Participant Registry**

Box 870348 | Tuscaloosa, AL 35487-0348

Phone: (205) 348-4253

Fax: (205) 348-8648

Email: idlab@ua.edu

Website: www.uaidpr.ua.edu

Get Involved!

Do you know someone who wants to join the registry or participate in our research projects?

Would you like your group or group's event to be listed in a future newsletter?

Let us know!

Call or email to get in touch!

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University of Alabama Intellectual Disabilities Participant Registry

Promoting Research on Intellectual Disability



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