WHAT IS THE INTELLECTUAL DISABILITIES PARTICIPANT REGISTRY?

The University of Alabama’s IDPR (AKA “The Registry”) is a database of families and individuals with intellectual disability who are interested in participating in behavioral research studies. We match families and individuals to appropriate studies to facilitate research on intellectual disability. The Registry currently covers Alabama, Mississippi, Georgia, and Florida. Call us at 205-348-4253 or email idlab@ua.edu for more information.

STUDIES CURRENTLY NEEDING PARTICIPANTS

Please contact the Registry for information!

Learning and Language Research Study

Dr. Fran Conners and her colleagues are examining how learning and memory work together to determine the development of language. Knowing this will help researchers suggest ways to improve teaching and therapy techniques for individuals with Down syndrome and other intellectual disabilities. This study is enrolling participants ages 10-21 with Down syndrome or another intellectual disability and participants ages 4-21 who are typically developing. This study is funded by the National Institute of Child Health and Human Development.

Wayfinding Research Study

This study is directed by Dr. Ed Merrill. It focuses on how children with and without Down syndrome learn to find their way through the environment. This skill is called wayfinding. This study is looking for participants ages 10-25 with Down syndrome or another intellectual disability and children ages 4-9 who are typically developing. This study is funded by the National Institute of Child Health and Human Development.

NEW STUDIES COMING SOON

Parenting Dimensions and Intellectual Disability

This study is being conducted by Allyson Phillips for her doctoral dissertation. The purpose of this study is to examine the way parents of children with intellectual disability are parenting their children and to understand if this is different than the way parents of typically developing children parent their children. This study will include mothers of children with intellectual disability who are between the ages of 5 and 12 years. Mothers will be asked to fill out a series of surveys that will take approximately 1 hour to complete.

Attention in Down Syndrome

This study is being conducted by Gayle Graham for her Master’s thesis. She is examining how auditory and visual sustained attention are affected in Down syndrome. Findings could help educators better understand how to teach these youth. For instance, if visual sustained attention is found to be a strength and auditory sustained attention is found to be a weakness, results would suggest educators use visual stimuli such as pictures, rather than auditory stimuli such as verbal direction, when teaching. This study will be enrolling participants with Down syndrome aged 10-21 years.
RESEARCH REVIEW: WAYFINDING IN DOWN SYNDROME

Many of you participated in a research study conducted by one of our faculty members, Dr. Edward Merrill. The study, *Wayfinding in Down Syndrome*, has been specifically interested in the wayfinding and navigation skills of children and young adults with Down syndrome.

Down syndrome has been linked to specific difficulties in cognitive performance that are associated with the functions of a specific area of the brain known as the Medial Temporal Lobe (MTL). One important role of the MTL is to assist in learning and navigation in the environment. Learning to get around the environment without getting lost is a necessary skill for independent living. Being able to find your way around a supermarket or shopping mall can enhance your quality of life. Therefore, it is important to evaluate how individuals with Down syndrome perform in these skills that are collectively known as “wayfinding.” The project that many of the children and young adults in the Registry completed was the first to compare wayfinding skills in persons with and without Down syndrome. This study looked at how well participants could follow a route to a destination. Also, it looked at how route learning was related to other cognitive skills. The goal was to identify some basic cognitive skills that support wayfinding and to see if they can be used to improve wayfinding abilities.

Individuals who took part in the study completed several measures. One was a basic measure of route learning in a “virtual” environment presented on a computer. Performance in a virtual environment is usually very similar to performance in a real environment and doesn’t require that participants walk around where distractions and fatigue can be a problem. The participants also completed a couple of general memory measures, a spatial learning/visual search measure, two measures of planning and reasoning, and parents completed a measure of executive function about their child. Executive functions are those general skills that are used to regulate thoughts and behaviors and include things like attention, inhibition, and monitoring.

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Early results from the study provided several pieces of information that we did not already know. First, the results showed clearly that individuals with Down syndrome have difficulties with wayfinding activities that are more than would be expected based on their general cognitive skills. Therefore, some effort will be needed to help young people with Down syndrome learn to find their way to the places they need or want to go.

Second, there is a big difference in the way that basic cognitive abilities are related to wayfinding skills in persons with Down syndrome vs. persons without Down syndrome. For example, among individuals without Down syndrome, those with better verbal memory performed better in wayfinding. However, among individuals with Down syndrome, those with better verbal memory actually performed worse in wayfinding. This tells us that participants with and without Down syndrome were using different cognitive skills to complete the wayfinding task.

Based on these results, we are in the process of developing some procedures that may enhance simple wayfinding by focusing the individual’s attention on learning important features of the environment. For example, it may be possible to expose individuals to video or pictures of the intended route in which the important landmarks and turns are highlighted to make them stand out. This may be helpful when actually following the route. In the meantime, we are trying to find out how much learning experience is needed for persons with Down syndrome to develop useful general knowledge of the environment.

Dr. Merrill would like to express his gratitude to all the families who participated in this research project. You have helped us learn more about how individuals with Down syndrome develop. This information will surely lead to even more important research in the field!
GET INVOLVED!!

If you would like your group’s event to be listed in our future newsletter, please let us know.

Sincere thanks to everyone who is helping the Registry to promote research on intellectual disability!

PROMOTING RESEARCH ON INTELLECTUAL DISABILITY

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Look Here for Upcoming Events in your Area:

**Alabama**
- Easter Seals: Champions for Tuscaloosa, May 17, Tuscaloosa
- C.A.S.T. for Kids: fishing event, May 18, Lake Guntersville

**Mississippi**
- Camp Dream Street, May 28 – June 1, URJ Henry S. Jacobs Camp, Utica
- www.dreamstreetms.org

**Georgia**
- 8th Annual Extra Special Easter Party, March 23, Nash Farm Battlefield, Hampton, GA

**Florida**
- Family Network on Disabilities: Scavenger Hunt and Pub Crawl
  May 18, Duendin
- Williams Syndrome Association Family Fun, May 11, St. Petersburg