

Visit our website at
www.uaidpr.ua.edu!

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 idl@ua.edu for more information.

NOTE FROM THE REGISTRY COORDINATOR

Dear registry families,

We have some amazing research opportunities on the horizon! Within this edition of the registry newsletter you will find information on an upcoming study looking at cognitive decline in individuals with Down syndrome. If you would like more information on this study please let us know.

Many of you participated in a study conducted by Dr. Jennifer Yang; the results of her study are provided in this newsletter. The registry makes a deliberate effort to give you the findings from studies that registry families participate in!

In response to immense parent interest regarding opportunities for post-secondary education in their areas, we have included information on some of the available programs within this newsletter. More information can be found at www.thinkcollege.net and on our website at www.uaidpr.ua.edu.

We also have a special guest in this newsletter, Liz Platchta, Executive Director and Co-founder of Ruby's Rainbow. Mrs. Platchta sat down with us to discuss some of the opportunities that her organization provides.

All of this in the Winter 2017 newsletter!

Eric

Find us on Facebook [@UAIDPR](https://www.facebook.com/UAIDPR)



SPOTLIGHT ON ELI JOHNS!

Eli is 2 years old and goes to the Rise School at The University of Alabama. He loves playing with his 4-year-old sister Katelyn, and especially her toys. He likes to paint, to play with his toy train and to be outside. He has a terribly contagious laugh and never meets a stranger. He loves music and is quite the entertainer with his dance moves!

WHATS INSIDE

- Findings from a registry supported study by Dr. Jennifer Yang – **pg. 2**
- Information on upcoming studies supported by the registry – **pg. 3**
- Profiles of new registry assistants – **pg. 3**
- Interview with Liz Platchta - **pg. 4**
- Information on post-secondary education programs for individuals with intellectual disability – **pgs. 5-7**

RESEARCH REVIEW: DR. JENNIFER YANG

Wayfinding Skills in Youth with Down Syndrome: What Parents Say

Dr. Yingying “Jennifer” Yang conducted an online survey to gather feedback from parents of children with Down syndrome (DS) about their child’s ability to navigate their environment, a skill known as wayfinding. Past studies have shown that wayfinding is difficult for people with DS, however little is known about their real-life wayfinding abilities. Many registry families participated in this study - thank you!

Dr. Yang’s study focused on 86 parents of young people with DS between the ages of 12-25. Participants completed an online survey on their children’s wayfinding behaviors and also provided some of their own feelings and expectations about their children’s wayfinding ability and wayfinding confidence.

There were several interesting findings from this study. Parents reported that their children had limited wayfinding knowledge, yet the children were very confident in their own wayfinding abilities. Over half of parents planned to teach their children wayfinding skills or had already done so; roughly 1/3 of parents did not plan on teaching these skills. A majority of parents were concerned about their children getting lost at least sometimes. Parents who reported lower levels of concern had taught their children some wayfinding skills and reported better wayfinding skills in their children. Future studies will need to focus on social and safety concerns, as well as cognitive aspects of wayfinding.

This study will be published in *Journal of Intellectual and Developmental Disability*. Co-authors with Jennifer Yang are Gayle. G. Faught, and Edward C. Merrill.

TAKE-HOME FOR PARENTS:

- 1.) Many parents of children with DS are worried about their children’s ability to navigate their environment. You are not alone!**
- 2.) Only a small portion of parents in this study tried or were planning to try to teach their children navigation skills. They were less worried, and felt their children were better at wayfinding. Parents may need guidance in whether, when, and how to teach these skills.**

TAKE-HOME TIPS FOR PARENTS



The registry is part of the Cognition and Intellectual Disability Lab at The University of Alabama run by Dr. Fran Conners. For more info go to connerslab.as.ua.edu.

UPCOMING REGISTRY-SUPPORTED STUDY:

Signs of Cognitive Decline in Adolescents and Young Adults with Down Syndrome

This study will be conducted by the Connors Lab at the University of Alabama as a pilot study for a potential grant-funded study in the future. One characteristic of Down syndrome is accelerated aging, which can include declines in memory and other cognitive skills. Another is heightened risk for Alzheimer's Dementia. In this study, we are trying to identify very early signs of cognitive decline in people with Down syndrome. Identifying these could lead to future treatments that could slow the decline. The goals of the study are 1) to identify early declines in memory and language, 2) to identify early behavioral changes (like sleep patterns and social engagement), and 3) to link the first two goals to symptoms of mild cognitive impairment. Mild cognitive impairment is a diagnosable condition and a risk factor for Alzheimer's Dementia.

In this study, parents will complete a set of surveys on their son or daughter's behavior and abilities. Also, individuals with Down syndrome will complete a battery of tasks measuring language and memory. The measures will be repeated after 1-2 years. For more information please contact the registry!

THINGS TO NOTE:

- Visit our website at www.uaiddpr.ua.edu. Let us know what you think!
- We need your pictures! If you have any family pictures you would like to share with the Registry, or if your children would like to draw us a picture we would love to have them! Any pictures sent in will be used either on our website or to decorate our offices!
- We would really like to expand the Registry to include more families. If you know someone who would like to join the Registry, please ask them to email or call us. Registration is also available online at our website!

REGISTRY ASSISTANTS

The registry is fortunate to have great assistants! They are bright, enthusiastic, and caring. Please meet Hayleigh Flores, Mary Beverly Finkbohner, and Rachel Lawrence.

HAYLEIGH FLORES



Hayleigh Flores is from Grand Rapids, Michigan. She is currently a sophomore double-majoring in Biology and Psychology on the Pre-Medical track. She spends time volunteering as a mentor to 2nd graders at a local elementary school, and she is also the assistant to the chapter president of her sorority. She enjoys being outdoors, reading and spending time with friends and family.

MARY BEVERLY FINKBOHNER



Mary Beverly Finkbohner is from Mobile, Alabama. She is currently a junior majoring in Psychology on the Pre-Physical Therapy track. She spends most mornings volunteering her time at Professional Therapy where she is able to help aid and observe patients in rehab. She enjoys going on runs or walks.

RACHEL LAWRENCE



Rachel Lawrence is from Peachtree City, Georgia and is currently a junior at the University of Alabama. She is a Biology and Psychology double major on the Pre-Physical Therapy track. In her spare time, she crochets and makes blankets for Project Linus, which is an organization that makes blankets for children that experience trauma.

Interview with Liz Platcha, Executive Director/Co-founder of Ruby's Rainbow



Photo from Liz Platcha's website

What is the mission of Ruby's Rainbow?

"My youngest daughter was born unexpectedly with Down syndrome. Shortly after her birth, we decided we wanted to do something for the Down syndrome community. We decided we wanted to focus our attention on what happens AFTER high school. There is so much stuff for the little guys, and so Ruby's Rainbow grants scholarship for postsecondary, vocational or enrichment classes. Also, we are spreading awareness for their capabilities."

Who is eligible to receive a scholarship from Ruby's Rainbow?

"They have to be 18 years of age and older, and they have to have Down syndrome. They must have a high school transcript, diploma or really just something to say they have completed high school."

What kinds of schools does Ruby's Rainbow provide scholarships for?

"It is nationwide. It can be a two-year or four-year college. It can be residential or non-residential. It can be a community college. We have given scholarships for some art classes and more enrichment type classes. Most of the scholarships we provide are for the two or four-year programs where they're either living on campus or can commute."

Do you have a message that you would like to share with families interested in applying for a scholarship?

"In our application process, we like for the young person with DS to fill it out to the best of their abilities because we really like to hear their voice and their own words. The family member or parent is welcome to fill in spots where they might want to add more information. We ask applicants to write an essay but a lot of parents write their own essay about their journey as well. The biggest thing we want families to know is that we want to get to know the applicant as best as possible. Pictures, videos, or anything to help us get to know them better is very much appreciated."

Interview conducted by Mary Beverly Finkbohner

POSTSECONDARY PROGRAMS

In this section of the newsletter we present a table with information about postsecondary programs in our surrounding states. Due to limited space we have not included all of the available information for these programs, however additional information can be found on our website as well as at www.thinkcollege.net. This of course is not an exhaustive list of programs, there are other opportunities which may be available, if you know of any that we have missed please let us know!

Program Name and Location	Degree or Certificate?	Housing?	Description
University of Central Florida IES Orlando, FL	No	Yes	Offers students with intellectual disabilities an inclusive, comprehensive non-degree seeking academic experience with a vocational focus. Program is designed to be 3 years in length. Students who have graduated from or completed K-12 system are eligible. <u>CONTACT</u> Adam Meyer, adam.meyer@ucf.edu
Florida Atlantic University Academy for Community Inclusion Jupiter, FL	Certificate	Beginning Summer 2017	A certificate program for students with intellectual and developmental disabilities who have graduated from high school with a diploma, G.E.D., or certificate. Provides students the opportunity to advance skills on a university campus with same age peers in inclusive setting. <u>CONTACT</u> Gwendolyn Carey, gcarey@fau.edu
LiFT University Transition Program Seminole, FL	Under Development	No	Provides a unique postsecondary experience that offers a perfect balance of academics, real-life socialization, career experience and life skills training to young adults with neurodiversities, empowering them with skills for successful independence. <u>CONTACT</u> Kim Kuruzovich, mrsk@liftacademy.org
The Learning Academy at University of South Florida Tampa, FL	Certificate	No	A 30-week, two semester program designed to help students with Autism Spectrum Disorder achieve a life of opportunity, independence and success. The intent of the program is to build and enhance skills that prepare students for the world of work or furthering their education. Courses include the provision of support and services that will facilitate success. <u>CONTACT</u> Susan Richmond, srichmond@usf.edu
Project ACCESS Key West, FL	Yes	Yes	Comprehensive transition and postsecondary program designed to support students with intellectual disabilities seeking to continue instruction at an institution of higher learning to prepare for gainful employment. <u>CONTACT</u> Karla Malsheimer, karla.malsheimer@fkcc.edu

Program Name and Location	Degree or Certificate?	Housing?	Description
Project 10 STINGRAY St. Petersburg, FL	Yes	Yes	Offers young adults with significant cognitive disabilities, ages 18 to 22, an opportunity to experience life on a college campus while developing self-determination, independent living, and employability skills. <u>CONTACT</u> L. Danielle Roberts-Dahm, lroberts@usfsp.edu
ACCESS Program at Mississippi State University Starkville, MS	Certificate	Yes	Promotes successful transition of students with intellectual disabilities into higher education. Provides inclusive opportunities for diverse learners to realize full potential with appropriate supports. Students participate in university catalog courses, live in on-campus residential housing, engage in professional internships, and enjoy an active social life with friends. <u>CONTACT</u> Elizabeth Williams, ewilliams@saffairs.msstate.edu
Clemson HOPE Clemson, SC	Pending	Yes	A living-learning community for individuals with intellectual disabilities. It is a 16-week semester program designed to give students a postsecondary experience that provides opportunities for learning and growth in residential, relational, vocational, and academic areas. <u>CONTACT</u> Kendra Perkins, kperkin@clemson.edu
Clemson LIFE Clemson, SC	Yes	Yes	Program designed for students with intellectual disabilities who desire a postsecondary experience on a college campus. The mission is to provide a coordinated course of study that includes career exploration and preparation through a framework of courses, job internships, and community participation. <u>CONTACT</u> Erica Walters, 864-656-0501
College of Charleston REACH program Charleston, SC	Yes	Yes	A four-year, fully-inclusive program for students with intellectual and/or developmental disabilities. The program promotes knowledge and skill in areas of academics, socialization, independent living, and career development, and has been recognized for its commitment to full inclusion and self-determination. <u>CONTACT</u> Edie Cusack, reachprogram@cofc.edu

Program Name and Location	Degree or Certificate?	Housing?	Description
CarolinaLIFE Columbia, SC	Yes	Yes	CarolinaLIFE is an innovative two-to-four-year postsecondary education program for students with intellectual or cognitive disabilities. Students enrolled in the program experience college life through inclusive participation in academic, social, vocational and independent living activities. <u>CONTACT</u> Anthony Plotner, plotner@mailbox.sc.edu
Coastal Carolina University LIFE Conway, SC	Yes	Yes	A four-year, post-secondary education and transition program for young adults who have mild to moderate intellectual disabilities. LIFE facilitates and supports each student's full inclusion within the campus community. <u>CONTACT</u> Zan Wiggins, biddlecenter@coastal.edu
University of Memphis TigerLIFE program Memphis, TN	Yes	Beginning in Fall 2017	A 60-hour postsecondary education program that provides study in the areas of academic, social, vocational, and independent living skills for students ages 18-29 with intellectual disabilities. <u>CONTACT</u> Maurice Williams, mwillia@memphis.edu
University of Tennessee FUTURE Program Knoxville, TN	Yes	No	This program focuses on a combination of academic, social, vocational, and independent living skills. Young adults who are 18 to 29 years old with an intellectual disability, developmental disability, learning disability, and/or autism are encouraged to apply. <u>CONTACT</u> tbeeson@utk.edu
Next Steps at Vanderbilt Nashville, TN	YES	Beginning in Fall 2017	Next Steps at Vanderbilt is a 2-year inclusive program committed to providing students with intellectual disabilities a transformational postsecondary education in academics, social and career development, and independent living. <u>CONTACT</u> Beverly Hand, Beverly.b.hand@vanderbilt.edu

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PROMOTING RESEARCH ON INTELLECTUAL DISABILITY

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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!

