

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 of all ages 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.

NOTE FROM THE REGISTRY COORDINATOR

Dear registry families,

2020 has without a doubt been a stressful time for many thus far with the COVID-19 pandemic dominating much of our lives; I hope that every one is staying well. Here at the registry we have not been conducting face-to-face research, but other aspects of the program have been in operation.

In this newsletter we highlight some opportunities for participation, including three projects funded by the National Institutes of Health. Most of the projects will begin only when it is safe for families, so please hang in there with us until then. These are important projects and you will have the opportunity to make a lasting impact by participating! Fortunately, one of the projects is being converted to remote format. This is the project looking at adolescents' math skills. In this newsletter we also provide results from a recently published study that many of you participated in.

We recently completed a family feedback questionnaire to gather information on ways to improve the registry. Thank you for participating! Highlights of those results are included in the newsletter. In addition, as we work to increase our presence on social media, we have included a short feature about our Facebook page. Find us on Facebook at <https://www.facebook.com/UAIDPR>.

And last, but certainly not least, August 14th will mark the end of my time here with the registry. I recently earned my Ph.D. in Communication (!) and will be moving to another position at the University of Florida. Working with you all over the past five years has been a wonderful experience. To show my appreciation I have put together some parting words along with an introduction to the new primary contact, Dr. Fran Connors.

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



SPOTLIGHT ON Dominique Portera!

Dominique Portera recently graduated from Hoover HS. She plans to continue working at Stone Salon in Hoover, while also attending Unless U, a postsecondary program for individuals with intellectual disability. Congratulations Dominique!

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UPCOMING STUDIES

Cognitive Change in Adolescents and Young Adults With Intellectual Disability

Dr. Fran Conners and Dr. Len Abbeduto, funded by NIH

This study is led by Dr. Fran Conners and is in collaboration with The University of California, Davis. It examines cognitive change in individuals with intellectual disability (ID). Memory, language, and nonverbal skills have different patterns of change over the lifespan, and there is concern that in intellectual disability (and in particular Down syndrome), the usual age-related declines may begin at a younger age than in the general population. In some cases, early declines are signs of developing Alzheimer's Disease. In this study, the researchers will identify aspects of cognition that begin to decline early as well as aspect of cognition that are still improving. Understanding the changes that occur during the adolescent-to-early adult years could lead to future treatments that could slow the decline. This study will be recruiting individuals with ID ages 15-25 years.

Numerical Skills in Children and Adolescents with Down syndrome

Kristina Baggett, master's thesis

Researchers have begun to examine the most basic numerical skills in children with Down syndrome (DS). Nonsymbolic numerical skills relate to judging quantities (e.g., more or less) without number symbols. Symbolic numerical skills relate to understanding number symbols and the quantities they stand for. Some studies suggest that children with DS are better with non-symbolic numerical skills than with symbolic number skills. For her master's thesis at UA, Kristina Baggett will examine both types of numerical skills by comparing participants with DS and participants who are typically developing at the same vocabulary level. Identifying potential differences between these groups could lead to ways of improving these skills. This study is being converted to remote format to begin in late Fall 2019. It will be recruiting children with DS ages 9-16 years as well as typically developing children ages 3-6 years.

Reading Comprehension in Children with Intellectual Disability

Dr. Susan Loveall and Dr. Fran Conners, funded by NIH

The Universities of Mississippi, Alabama, and Nebraska are collaborating on this study of reading comprehension skills in individuals with intellectual disability. Often, children with intellectual disabilities do much better with word identification than with reading comprehension. This study looks at why, by examining the relation of language skills to reading comprehension. Understanding the reasons for difficulties in reading comprehension may lead to better ways to teach reading to children with intellectual disabilities. This study will be enrolling participants with intellectual disability, ages 10-15 years, as well as participants who are typically developing, ages 6-10 years.

Spatial Malleability in Down Syndrome

Dr. Ed Merrill and Dr. Jennifer Yang, funded by NIH

This UA study is in collaboration with Montclair State University in New Jersey. Previous research has shown that individuals with Down syndrome (DS) often struggle with finding their way to a destination. There may be many reasons for this, but this study looks at underlying spatial abilities as a reason. The purpose of the study is to find out if underlying spatial abilities can be improved through experience with games, puzzles, and Legos. The study will be recruiting individuals with DS, ages 10-25 years and typically developing children ages 4-9 years.

**IF YOU ARE INTERESTED IN ANY OF THESE STUDIES OR WOULD LIKE
MORE INFORMATION PLEASE CONTACT REGISTRY STAFF AT
IDLAB@UA.EDU OR AT 205-348-4253.**

RESEARCH REVIEW: DR. FRAN CONNERS

Previous research suggests that individuals with Down syndrome (DS) often struggle with receptive language (ability to understand information) and expressive grammar (ability to put thoughts and words into sentences). These are important skills because they contribute to school learning and social interactions. A team of researchers led by Dr. Fran Connors conducted a study examining how aspects of language and phonological memory (immediate memory for speech and sound sequences) develop among adolescents with DS. Participants completed a set of language and phonological memory tests twice, two years apart.

The research team tested 42 individuals with DS who were ages 10-21 years (many from the registry - thank you all!). The findings suggest that receptive and expressive grammar remained stable over this 2-year period, while receptive vocabulary improved during this time. Findings were mixed for phonological memory, with clear declines showing in one of two measures.

The strength of receptive vocabulary and its improvement over time suggest that this skill could be capitalized on in communication in social and work settings. The possible decline in phonological memory could be a sign of early cognitive aging in DS. If so, it could be used to signal the need for intervention. The research team recently received a large 5-year 2-site grant from the National Institutes of Health to replicate and extend these findings.

The reference to the published study is:
Connors, F. A., Tungate, A. S., Abbeduto, L., Merrill, E. C., & Faight, G. G. (2018). Growth and decline in language and phonological memory over two years in adolescents with Down syndrome. *American Journal on Intellectual and Developmental Disabilities*, 123, 103-118.

TAKE-HOME TIPS FOR CAREGIVERS:

- 1. Your son or daughter with Down syndrome may have better vocabulary understanding than it seems. Introduce new words to them from time to time to help them expand their vocabulary further. Encourage them to use their new words. This can only improve their ability to communicate with others!**
- 2. Recognize that your son or daughter with Down syndrome may have difficulty capturing long verbal messages. Make sure they are paying attention first, then keep your verbal message short, and check if they got it.**

TAKE-HOME TIPS FOR CAREGIVERS

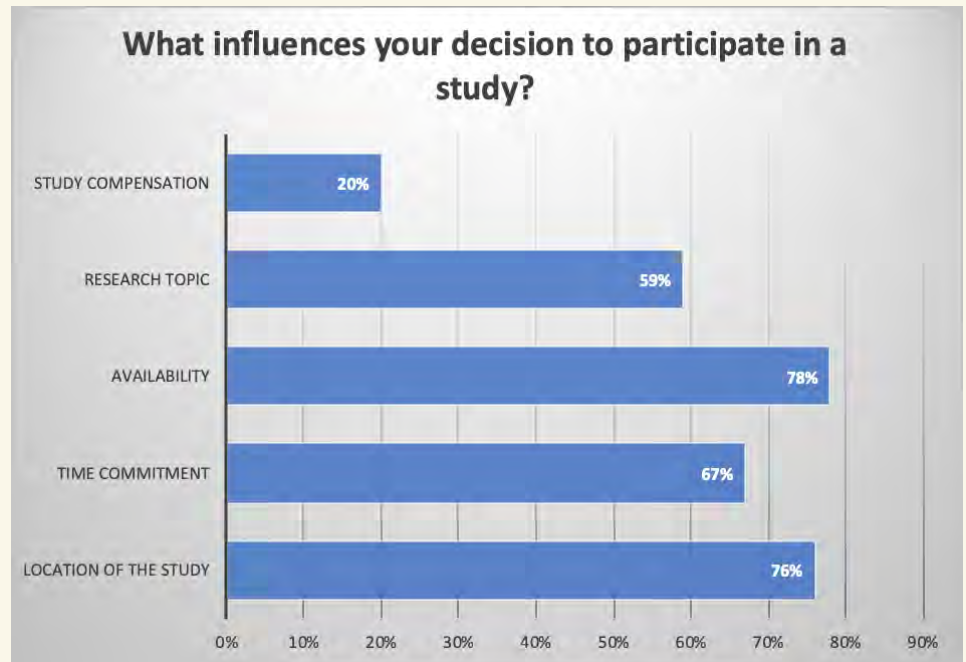


A coauthor on this study, Dr. Andrew Tungate is now Lead Data Manager at the University of North Carolina Institute for Trauma Recovery.

HIGHLIGHTS OF REGISTRY SURVEY RESULTS

A survey was distributed to get feedback on ways in which the registry can improve its operations, and nearly 70 families participated; thank you! Here are some highlights of the results.

Families were asked about things that motivated them to participate in studies when asked; the numbers in the chart represent the % who felt the reason was either "somewhat" or "very" important. Families reported that the most important factor is availability (78%), followed by study location (76%). The time commitment required (67%) followed by study topic (59%) were also considered as relatively important, whereas study compensation was only rated as somewhat or very important by 20% of families.

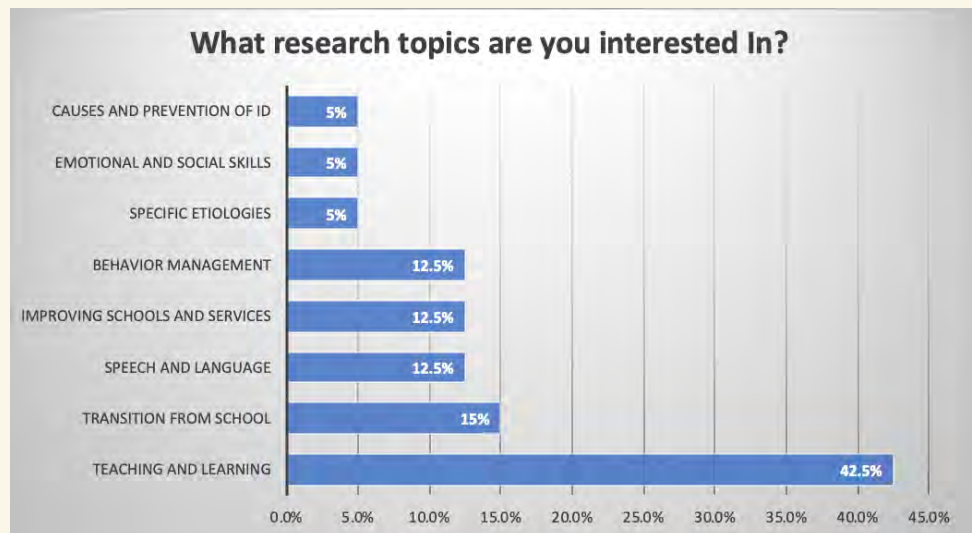


Families also provided insight on ways that the registry can better communicate. Nearly half of families suggested that more attention should be paid to providing information about study results and how these outcomes will benefit individuals with ID. While many families felt that no changes needed to be made, others felt a need for more diversity in the methods for communication and more frequent communication overall.



HIGHLIGHTS OF REGISTRY SURVEY RESULTS

Families discussed their ideas for future research topics that should be supported by the registry. The most commonly mentioned topic, by a large margin, was teaching and learning (43%). Families were also highly interested in studies focused on transition, as well as speech and language, behavior management, and improving services.



This information will be used to improve the registry so that it can better serve families and researchers moving forward. Thank you again for your participation!

FACEBOOK FEATURE

The registry Facebook page is not only a place for information about research, it is also a chance to share the achievements of our families and other stories that are relevant to individuals with intellectual disability.

One of our long time members, Erech Brown, is an amazing artist who has been kind enough to share his work with us over the years. The piece you see below is entitled "Gecko." Erech hopes to one day have his own business that will allow him to share his passion with the world. There is no doubt that he will be successful. Good luck Erech!

We also recently highlighted the outstanding work of our research assistants. Ann Marie Young, Kara Acosta, Tori Smitherman, and Andrea Nicastro participated in the 2020 Psychology Conference at Troy University held virtually in March. While COVID-19 put an end to on-campus instruction, these students rose to the challenge and showed great perseverance in presenting their findings in a virtual setting. Great job everyone!

To get more information and news find us on Facebook facebook.com/UAIDPR.



PARTING WORDS/SPOTLIGHT ON NEW CONTACT

Over the five years that I have served as coordinator for the UAIDPR I have met so many families, advocates, and other stakeholders that are passionate about and heavily invested in the ID community; these experiences have helped to shape the way that I work and will continue to inspire me moving forward. I have also had the opportunity to work alongside researchers who have made it their life's work to increase our knowledge about ID. I want to thank the director of the UAIDPR, Dr. Fran Connors, for her vision. Dr. Connors truly cares about this community and it shows in her work. I know she will lead the UAIDPR well into the future.



I also want to thank all of the families and organizations for welcoming me and for supporting our research. During this five-year period the size of the UAIDPR has grown by nearly 15% and we have served more than a dozen research studies, including several dissertations which have launched the careers of the next wave of leaders in the field of ID research. Although I am stepping away from this position, my role as an ally for the ID community will not change. I will continue to assist in any way that I can.

My interest in research on ID is not just professional but also personal as my daughter Isabella is a member of the program and participates in research studies. She keeps us on our toes and we will continue to seek out the best opportunities for her, as will all of you for your own families. The purpose of research is to generate knowledge, and in this field it cannot be done without your involvement. Thank you for being a part of the UAIDPR. Feel free to keep in touch with me through email, cooks002@gmail.com - Eric





Moving forward, Dr. Fran Connors will take on the role as primary program contact at least for the near future. Dr. Connors has been the principal investigator for the UAIDPR since its inception in 2009. She has over 30 years of experience in intellectual disabilities research. Please do not hesitate to contact her with any questions. To provide you with a little more information on Dr. Connors, here is an excerpt from a 2018 interview:

What are some of the biggest advances you've seen in your field over the years?

Probably the biggest advance is the understanding that people with intellectual disabilities can learn and can be a part of society. It is hard to believe now that this is an advance, but yes, there was a time when this was not understood. This knowledge has led to more inclusion in educational and community settings and better ways of teaching students with intellectual disabilities. Another advance has been understanding more of the causes of intellectual disabilities. Some intellectual disabilities are due to genetic causes (e.g., Down syndrome and fragile x syndrome), some are due to toxins (e.g., fetal alcohol syndrome), and some causes are unknown. Knowledge of these causes has led to prevention programs and even potential pharmaceutical treatments.

What is the goal of your lab?

We study behavioral aspects of intellectual disability, especially Down syndrome. We study aspects of cognitive, linguistic, and most recently social functioning to find out where the real challenges lie and where the the relative strengths are. But we are concerned with how the challenges and strengths factor into everyday functioning of individuals with intellectual disability - such as the ability to read, the ability to find one's way, the ability to communicate and the ability to get along with others.

Why is it important to get families involved in research on intellectual disability?

By far, most of what we know about intellectual disability has been learned from individuals who have intellectual disability. Yet, the greatest barrier to our research is recruiting participants with intellectual disability. The more families get involved in research, the more we can learn, and the better life can become for individuals with intellectual disability. Research progresses slowly, so those who become involved today will be helping those of tomorrow.

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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!*



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