

WHAT IS THE INTELLECTUAL DISABILITIES PARTICIPANT REGISTRY?

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

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 cooks002@ua.edu for more information.

NOTE FROM THE REGISTRY COORDINATOR

Dear registry families,

Welcome to the 10th anniversary edition of the registry newsletter! In 2009 the registry was created to serve families and research studies investigating intellectual disability.

In the past 10 years, thanks to support from families like yours, we have been able to produce significant research results, and train future professionals that will assist in teaching the next generation of young people about intellectual disability.

In this issue of the registry newsletter we celebrate our accomplishments by providing updates from some of our registry families and previous graduate students who have since moved on from the University. There is also a section that covers some of the significant findings from previous studies that your family may have participated in, as well as information about current and upcoming opportunities.

As always if you know of anyone who might be interested in our program please send them our way; new families are always needed to continue with our mission of increasing knowledge of intellectual disability.

All of this in the Summer/Fall 2019 edition of the UAIDR newsletter!

Eric

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SPOTLIGHT ON Wyatt Putman!

Wyatt Putman just celebrated his 10th birthday! He loves his family, reading, SnoBalls, walking the beach, pizza, playmobil, burgers and fries, hugs, selfies, running track, his therapists, baseball, and going to church!

WHATS INSIDE

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CURRENT REGISTRY-SUPPORTED STUDIES:**Well-being and the Social Experiences of Adolescents with Down Syndrome****Jenna Reardanz, Dr. Fran Conners, and Dr. Kristina McDonald**

Research shows that children and adolescents with intellectual disability are at a higher risk to experience peer victimization compared to their typically developing peers. This study develops measures for this population that will be used in future research on the possible consequences of peer victimization, such as anxiety, depression, acting out, etc. The information learned in this study will be used to obtain federal funding for a larger study. The study is recruiting adolescents with intellectual disability ages 11-18.

Signs of Cognitive Change in Young Adults and Adolescents**Dr. Fran Conners**

This study is being conducted by Dr. Fran Conners 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, and another is heightened risk for Alzheimer's Dementia. In this study, we are trying to identify very early signs of declining cognitive skills in people with Down syndrome, as well as signs of improving skills. Identifying these signs could lead to future treatments that could slow the decline. This study is currently recruiting individuals with intellectual disability ages 14-29.

UPCOMING STUDIES:**The Approximate Number System in Children with Down syndrome****Kristina Baggett**

Recent research has begun to examine the most basic number skills in children with Down syndrome (DS). Several studies suggest that NON-SYMBOLIC number skills are preserved in children with DS, but deficits are found relative to typically developing children when it comes to SYMBOLIC number skills. For her master's thesis, Kristina Baggett is proposing a study under the supervision of Dr. Fran Conners to examine the development of both symbolic and non-symbolic number skills in children with DS. Identifying potential differences between children with DS and their typically developing peers could lead to future interventions to improve these skills. This study, which is scheduled to begin Fall 2019, will be recruiting children with DS ages 9-16.

**IF YOU ARE INTERESTED IN ANY OF THESE STUDIES OR WOULD LIKE
MORE INFORMATION PLEASE CONTACT THE REGISTRY COORDINATOR AT
COOKS002@UA.EDU OR AT 205-348-4253.**

Lilly Miller joined the registry in April of 2010; here she is on the left at 6 years old and on the right celebrating her Sweet 16!



Isaiah Palos joined the registry in November of 2010. He is a rising 9th grader and won 3rd place in basketball and 1st place in the 50 meter run recently at the Alabama State Special Olympics. Great job Isaiah!



Hannah Baker, who has been with the registry since November 2010, is a rising high school junior and is pictured below at the Next Steps at Vanderbilt Summer Institute (NSSI), an inclusive higher education preparatory experience designed to orient students and families to college life.



Kai Bohannon joined us in March 2010. She is 12 years old and also competes at the Special Olympics; Go Kai!

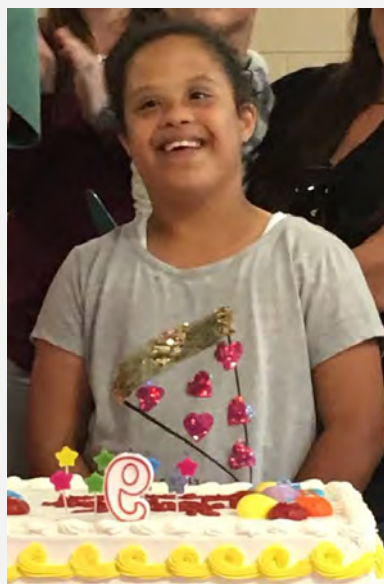
Over the past year **Jaden Walker** has been living his best life! After spending his first 13 months of life in the hospital he was discharged July 2018 and has been home ever since! Jaden has been with the registry since August 2017 and recently began the RISE program!



Let's welcome **Tayler Short** to the registry! Joining us in April 2019, Tayler is autistic and nonverbal. He is also a huge Alabama and Auburn football fan!



Isabella Cooks has been with the registry since 2015; she recently started the 4th grade and is a big fan of JoJo Siwa and the TV show The Voice!



George Merchant, who has been with the registry since 2015, recently participated in Hewitt Trussville's baseball camp; it is by far his favorite summer event. George's 2A baseball team, the Bucs, won Homewood's Joy League championship. Great job George!



Gabe Ford is an active 5-year-old boy that loves to chase and be chased by his mom, dad, and three big brothers. Gabe has an immune disorder that doesn't allow him to participate in other activities that most 5-year-old children get to enjoy. Gabe loves to rock, swing, jump, and bounce. Gabe recently joined the registry in February, welcome Gabe!



Beth Olive, a registry member since September 2010, was chosen to represent the United States at the Special Olympics World Games; after 7 months of training with her coach in Alabama she joined Team USA and traveled to the games held in Dubai and Abu Dhabi in UAE. One of six gymnasts representing the U.S. in a field of 261 gymnasts from around the world, she represented and brought home silver on ribbon, bronze on hoop and rope, 4th place on clubs and bronze All Around!! There were 20,000 volunteers and 7000 athletes participating in 26 sanctioned sports. It was the adventure of a lifetime!



Laurel Brown, who has been with the registry since 2010, graduated from Mountain Brook High School and has worked in the cafeteria at Samford for four years. Her hobbies include knitting, going out to eat, and playing Sims. Laurel lives independently and loves the going to the movies and restaurants.





Dr. Marie Channell

Dr. Channell earned her PhD in Developmental Psychology from the University of Alabama in 2012. Following her PhD, she spent 3 years as a post-doctoral fellow at the University of California, Davis MIND Institute, where she received interdisciplinary training in the Autism Research Training Program (NRSA T32, NIMH). She joined the faculty of Speech and Hearing Science at the University of Illinois at Urbana-Champaign as an Assistant Professor in 2015. Dr. Channell's research aims to better understand how individuals with Down syndrome and other types of intellectual disability learn to communicate.



Dr. Jennifer Yang

Yingying (Jennifer) Yang graduated with a Ph.D. in developmental psychology from the University of Alabama in 2015. Jennifer studies how people with Down syndrome interact with the spatial environment and how they remember their surroundings. This line of research can help to design better spatial environments for individuals with intellectual disability. Jennifer is currently a tenure-track assistant professor at Montclair State University, the 2nd largest university in the state of New Jersey and 14 miles away from New York City.



Dr. Gayle Faught

After graduating in 2017 with her PhD, Dr. Faught taught at The University of Alabama as an Instructor of Psychology for one academic year. Since then, she has been an Assistant Professor of Psychology at the University of South Carolina Aiken. The move to South Carolina was big for her family, which has recently added a new member. Her daughter, Alice, was born April 17th, and her big brother is thrilled.



Dr. Allyson Phillips

Allyson Phillips is Assistant Professor and Chair of Psychology at Ouachita Baptist University in Arkadelphia, AR. She teaches undergraduate students and continues to do research in developmental psychology. Her most recent work involved facial emotion recognition training for children with autism. In addition to her work, her family has continued to grow since graduate school, and she and her husband now have three children -- Jordyn (age 6), James (age 4), and Calvin (just born!).



Dr. Andrew Tungate

After graduating Andrew took a job with the Institute of Trauma Recovery a research group at UNC Chapel Hill. He functions as a data manager / junior-level statistician. He feels fortunate to work on studies that help different types of trauma survivors e.g. veterans, sexual assault survivors, thermal burn injury survivors, and motor vehicle collisions survivors. Andrew is also working on publishing his dissertation on executive function in Down syndrome, and he and his wife recently welcomed twin babies into the world!



Dr. Susan Loveall

Susan Loveall completed her PhD in Cognitive Psychology and Developmental Science at the University of Alabama in 2013. After graduation she completed a two-year postdoctoral fellowship at the LifeSpan Institute at the University of Kansas, focused on reading interventions for children with intellectual and developmental disabilities. She then worked as an assistant professor in Communication Sciences and Disorders at the University of Mississippi for four years. This fall she will begin a new position in the Special Education and Communication Disorders Department at the University of Nebraska - Lincoln, where she will continue to study cognition, language, and literacy in Down syndrome and other developmental disabilities.



Dr. Megan Davis

Upon finishing her Ph.D. in Developmental Psychology in 2013, Dr. Megan Davis became the Assistant Coordinator for The University of Alabama Autism Spectrum Disorders College Transition and Support Program (UA-ACTS). UA-ACTS provides support services for UA students with autism to help with academic organization, social skills, daily-living and career-building skills, and emotional adjustment. Dr. Davis recently became the UA-ACTS Program Director in 2018 and hopes to continue to increase access to services and expand services for college students with an autism diagnosis. Dr. Davis currently resides in Tuscaloosa with her husband, Mark, her two-year-old son, Camden, and her dog, Allie. Roll Tide!

RESULTS FROM REGISTRY SUPPORTED STUDIES**LANGUAGE**

Loveall, S. J., Channell, M. M., Abbeduto, L., & Conners, F. A. (2019). Verb production by individuals with Down syndrome during narration. *Research in developmental disabilities*, 85, 82-91. (Funded by NICHD)

This study focused on the use of verbs when narrating a story. Verb use is a major characteristic of structural language, which is important for communication. In this study, participants were asked to narrate a story aloud from a wordless picture book. Adolescents with DS produced as many different verbs as typically developing children of similar cognitive level. However, they did not actually use verbs as frequently during story narration. Thus, for some reason, adolescents with DS are restricted in readily producing the verbs they have in their vocabulary. More research is needed to understand why and how to encourage wider use of verbs.

Conners, F. A., Tungate, A. S., Abbeduto, L., Merrill, E. C., & Faught, G. G. (2018). Growth and decline in language and phonological memory over two years among adolescents with Down syndrome. *American journal on intellectual and developmental disabilities*, 123(2), 103-118. (Funded by NICHD).

The purpose of this study was to examine changes in language and phonological memory during the adolescent period. Phonological memory is brief memory for ordered speech sounds, such as lists of digits, or nonword sound sequences (eg., juperate, as spoken aloud). It is important for speaking and understanding spoken language. In this study, adolescents with Down syndrome completed language and phonological memory tests twice, 2 years apart. Results showed some growth, some stability, and some decline depending on the specific skill. Specifically, there was growth in receptive vocabulary, stability in receptive grammar, and decline in phonological memory. There were also some more complex patterns. The results suggest that adolescence is a time in which both upward development and possibility early signs of decline are present for those with Down syndrome. These patterns may reveal key points in development at which interventions may be best applied.

Channell, M. M. (ongoing). Spoken language development in Down syndrome. (Funded by NICHD)

This study looked at how children with Down syndrome tend to talk about other people's mental states, such as feelings, thoughts, desires, and intentions. Use of mental state language indicates a type of connection with other people. Children were asked to tell a story from a picture book, and researchers recorded the different words the children used to describe the mental states of the characters. The most common mental state words were emotion words, such as happy, sad, and cry, suggesting that children with DS attend to others' feelings moreso than their thoughts, desires, or intentions. Children with more advanced language abilities and more emotion knowledge used more mental state language.

Loveall, S. J., Channell, M. M., Phillips, B. A., Abbeduto, L., & Conners, F. A. (2016). Receptive vocabulary analysis in Down syndrome. *Research in developmental disabilities*, 55, 161-172. (Funded by NICHD)

Particularly striking in individuals with Down syndrome (DS) is difficulty with speech and language. Receptive vocabulary, however, is often one of the stronger language aspects. This means that individuals with DS can use words to understand language much better than they can use words to explain or express their thoughts. Individuals with intellectual disability (ID) but not DS do show this pattern as strongly. This study looked at whether some types of vocabulary words might be easier or harder for adolescents with DS and adolescents with ID. We found that, for adolescents with DS, receptive vocabulary overall was at cognitive level and nouns were easier than verbs and attributes. For adolescents with ID, receptive vocabulary overall was higher than cognitive level, and both nouns and verbs were easier than attributes. These results point out differences in specific aspects of language based on the cause of intellectual disability.

Faught, G. G., Conners, F. A., & Himmelberger, Z. M. (2016). Auditory and visual sustained attention in Down syndrome. *Research in Developmental Disabilities*, 53, 135-146. (based on Gayle Faught's master's thesis).

Auditory tasks are often more difficult for youth with DS, compared with visual tasks. The present study looked at whether this could be due to differences in sustained attention in auditory vs. visual modalities. Sustained attention is the ability to hold focus on a task for an extended period of time, and is important to school learning and development of higher skills. This study investigated if sustained attention for looking vs listening might be a special challenge for youth with Down syndrome. Results showed that sustained attention was as expected for cognitive level in youth with DS, and there was no advantage for visual over auditory modality. Thus, it seems that special difficulties on auditory tasks for youth with DS are not caused by special difficulties in auditory sustained attention.

READING

Loveall, S. J., & Conners, F. A. (2016). Reading skills in Down syndrome: An examination of orthographic knowledge. *American Journal on Intellectual and Developmental Disabilities*, 121(2), 95-110. (based on Susan Loveall's doctoral dissertation).

It was once believed that individuals with intellectual disabilities could not learn to read. Today, we know better. The present study examined the types of skills and knowledge that influence word reading ability in youth with Down syndrome. Phonological recoding is the skill of using letter-sound correspondences to sound out words. Orthographic knowledge is knowledge about the letter combinations that make up words. Reading a word can be done by sounding out, or by recognizing the letter pattern of the word, or by a combination of these. In this study, we found that, for their word reading level, youth with Down syndrome were especially challenged by phonological recoding and by general orthographic knowledge, but they were relatively better on word-specific orthographic knowledge. This suggests that their use of letter patterns may help them with word reading more so than their use of letter-sound correspondences. Thus, students with DS may need more support for phonological recoding and acquiring generalized orthographic knowledge; yet their stronger word-specific orthographic knowledge may be capitalized on to broaden their reading vocabulary.

LEARNING

Phillips, B. A., Conners, F. A., Merrill, E., & Klinger, M. R. (2014). Rule-based category learning in Down syndrome. *American Journal on Intellectual and Developmental Disabilities*, 119(3), 220-234. (based on Allyson Phillips' master's thesis, funded by NICHD).

Categories are important to everyday life; for example, it is important to know if an object is edible or not, and to know if a line figure is a letter or a number. One system of categorization is a rule-based system that involves simple categories whose rules are easily verbalized (color, shape, size etc.). The present study looked at rule-based category learning in youth with intellectual disability with and without DS. Results showed that this is a special difficulty for youth with intellectual disability. They performed lower on two rule-based category learning tasks than would be expected based on their cognitive level. This suggests that special support in learning categories might be helpful for children with intellectual disability.

Faught, G. G., Conners, F. A., & Himmelberger, Z. M. (2016). Auditory and visual sustained attention in Down syndrome. *Research in Developmental Disabilities*, 53, 135-146. (based on Gayle Faught's master's thesis).

Auditory tasks are often more difficult for youth with DS, compared with visual tasks. The present study looked at whether this could be due to differences in sustained attention in auditory vs. visual modalities. Sustained attention is the ability to hold focus on a task for an extended period of time, and is important to school learning and development of higher skills. This study investigated if sustained attention for looking vs listening might be a special challenge for youth with Down syndrome. Results showed that sustained attention was as expected for cognitive level in youth with DS, and there was no advantage for visual over auditory modality. Thus, it seems that special difficulties on auditory tasks for youth with DS are not caused by special difficulties in auditory sustained attention.

WAYFINDING

Himmelberger, Z. M. (2018). Acquisition of survey knowledge across repeated exposures to a novel environment in individuals with Down syndrome. Dissertation completed at The University of Alabama.

Young adults with Down syndrome (DS) often have difficulty with wayfinding. Wayfinding is the important skill of navigating an environment to get to an intended endpoint (e.g., finding one's homeroom from the front door of the school). It can be done by following step by step directions or by learning the layout of an area and using that knowledge to find the way. Shortcuts are more possible when the layout of the area has been learned. In this study, young adults with DS had the opportunity to find shortcuts in a virtual environment, over multiple exposures to the environment. It was difficult for them to find shortcuts, and in particular, they did not learn from the first exposure to the environment, as did typically developing children who were at the same cognitive level. Thus, individuals with DS may need more experience with an environment to learn to find their way in it. Alternatively, they may benefit from using wayfinding technology.

Yang, Y., Faught, G. G., & Merrill, E. C. (2018). Parent reports of wayfinding by their children with Down syndrome. *Journal of Intellectual & Developmental Disability*, 43(4), 483-493.

Navigating the environment, or wayfinding, is important to independent living. Studies indicate that wayfinding ability is a special difficulty in individuals with Down syndrome (DS); however, little is known about their real-life wayfinding abilities. In this study, parents of children with DS completed a survey on their children's wayfinding behaviors as well as their own feelings and expectations. Parents reported their children had few wayfinding skills yet they had much confidence in their own wayfinding abilities. Parents expressed concerns about their children's independent wayfinding, and many had taught or planned to teach their children wayfinding skills.

Davis, M., Merrill, E. C., Conners, F. A., & Roskos, B. (2014). Patterns of differences in wayfinding performance and correlations among abilities between persons with and without Down syndrome and typically developing children. *Frontiers in psychology*, 5, 1446. (Based on Megan Davis' master's thesis, funded by NICHD).

Down syndrome (DS) impacts areas of the brain that are responsible for aspects of navigation and wayfinding (finding one's way to an intended place). Therefore, it is very possible that DS may result in reduced ability to engage in these skills. This study evaluated route-learning, which involves learning to travel along a specific path and making specific turns to reach the goal location. Youth with DS displayed difficulties in route learning, beyond what would be expected for their developmental or intellectual level.

SOCIAL

Reardanz, J., Conners, F.A., & McDonald, K.L. (in press). Peer victimization and communication skills in adolescents with Down syndrome: Preliminary findings. *Journal of Autism and Developmental Disorders*.

This study had two main goals. First, to learn more about measurement of social topics, like peer victimization, in adolescents with Down Syndrome. Second, we wanted to learn more about the relationship between communication skills and peer victimization. This is one of the first studies to look at this relationship and is important to help us better understand individuals who may be at the highest risk for being victimized. In this study we found that adolescents with Down Syndrome who have better communication skills are less likely to be victimized. Additionally, when we compared the rates of victimization to typically developing adolescents, we found that those with Down Syndrome are more likely to report being victimized than their typically developing peers.

Phillips, B. A., Conners, F., & Curtner-Smith, M. E. (2017). Parenting children with down syndrome: An analysis of parenting styles, parenting dimensions, and parental stress. *Research in developmental disabilities*, 68, 9-19. (based on Allyson Phillips' doctoral dissertation).

Parenting style can influence a child's intellectual, physical, social, and emotional development. However, to some extent, child characteristics can affect parenting style. This study compared parenting styles in mothers of children with Down syndrome (DS) and mothers of typically developing (TD) children. We found that mothers of children with DS were less likely to use an authoritative parenting style and more likely to use a permissive parenting style compared to mothers of TD children. Mothers of children with DS also used verbal hostility less and ignoring misbehavior more than did mothers of TD children; these differences were accounted for somewhat by higher levels of parental stress in the DS group.

Channell, M. M., Conners, F. A., & Barth, J. M. (2014). Emotion knowledge in children and adolescents with Down syndrome: A new methodological approach. American journal on intellectual and developmental disabilities, 119(5), 405-421. (based on Marie Channell's doctoral dissertation).

Emotion knowledge is an umbrella term that includes the ability to reflect on one's own emotions, recognize emotional expressions in others, label those emotions, and identify causes of emotions. It is important for making friends and getting along in school and work settings. This study looked at emotion knowledge in adolescents with Down syndrome, using a dynamic measure that reduced the demand for language skills. We found that adolescents with DS were as accurate would be expected based on their developmental level when judging emotions from facial cues. This was true across a range of developmental level.

OTHER

Channell, M. M., Phillips, B. A., Loveall, S. J., Conners, F. A., Bussanich, P. M., & Klinger, L. G. (2015). Patterns of autism spectrum symptomatology in individuals with Down syndrome without comorbid autism spectrum disorder. Journal of neurodevelopmental disorders, 7(1), 5. (Funded by NICHD).

Comorbidity estimates of autism spectrum disorder (ASD) among those with Down syndrome (DS) differ widely. To some degree, these differences may be due to difficulty diagnosing ASD in individuals with DS. This study looked at autism symptoms in an autism-free sample of adolescents with DS, using parent report. We found that two autism symptoms were fairly common in DS – (1) autism mannerisms and (2) challenges in social cognition. These findings help to highlight the need to develop ASD tests specifically for individuals with DS.

Tungate, A. (2016). The relationship between exercise and executive function in individuals with Down syndrome. Master's thesis completed at The University of Alabama.

There are well known health benefits of exercise, and there may also be cognitive benefits. Andrew's master's thesis looked at the relation between everyday physical activity (as measured by pedometer steps) and parent-reported executive function in youth with Down syndrome (DS). Executive functions are the control aspects of cognition, such as inhibition, shifting, and working memory. Andrew found that adolescents wore the pedometer more consistently than children. For those who wore it consistently, number of steps per day was below the level expected for their age, suggesting that youth with DS need more daily physical activity. However, number of steps was not related to executive function.

Phillips, B. A., Loveall, S. J., Channell, M. M., & Conners, F. A. (2014). Matching variables for research involving youth with Down syndrome: Leiter-R versus PPVT-4. Research in developmental disabilities, 35(2), 429-438. (Funded by NICHD).

Much of what is known about the cognitive abilities of individuals with intellectual disability (ID) and Down syndrome (DS) in particular comes from using either receptive vocabulary (words that a person can comprehend and respond to, tested using the PPVT) or nonverbal ability (tested using the Leiter) as a baseline to represent developmental level. Our results suggested that the PPVT and Leiter are interchangeable at least for some outcome measures when comparing youth with TD and DS, but results may differ when comparing youth with ID and TD.

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PROMOTING RESEARCH ON INTELLECTUAL DISABILITY

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*Sincere thanks to everyone who is
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