

INTELLECTUAL DISABILITIES PARTICIPANT REGISTRY

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.

[Emotion Recognition Study](#)

Marie Moore, a psychology doctoral student, is leading a study on emotion recognition. She is looking at how well children and adolescents with Down syndrome recognize and understand other people's emotions. **Thanks to an overwhelming response, Marie has collected enough data for this study and will have results for us soon!**

Check out what everyone is doing!



LILLY'S CHEERLEADING, JANE'S SAILING IN GREECE, UNIVERSITY OF ALABAMA'S BUDDY WALK TEAM

[Attention Study](#)

This study is examining how implicit learning and attention interact. Implicit learning is learning by examples instead of rules. Researchers are looking for individuals with intellectual disability who are on kindergarten level or above, age is not a factor.

MEET YOUR NEW REGISTRY COORDINATOR!!



Allyson Phillips, Registry Coordinator and Graduate Assistant. Allyson received her B.A. in Psychology from Colorado Christian University and is a graduate student in the Developmental Science Ph.D. program at UA. She has worked with many Registry families as a researcher on the Learning and Language Study and is excited about working with everyone else as well!

RESEARCH REVIEW: TRANSITIONING TO ADULTHOOD

Everyone experiences major life changes when transitioning from adolescence to adulthood. Due to the drastic alterations to daily life, young people and their families can experience added stress. Typically developing individuals usually go to college or enter the workforce during this transition, but individuals with intellectual disability sometimes find their post-school options to be more limited. As individuals with intellectual disability leave the school system, parents must look for appropriate programs and services, which can prove to be very challenging and can cause added stress for individuals and families.

Neece, Kraemer, and Blacher (2009) examined transition satisfaction and family well-being for 128 parents of young adults with intellectual disability (ages 19-28 years). Parents were asked to complete a series of questionnaires that measured demographics, transition experience, parental involvement in transition, parental depression, family impact, young adult adaptive behavior, young adult mental health, and young adult quality of life. Further, through field notes from the experimenters, measures of transition satisfaction and family well-being were derived.

These researchers found that higher parental transition satisfaction was related to increased young adult mental health and quality of life and to increased parental involvement in transition planning. Further, they found that lower parental transition satisfaction was related to the family being impacted negatively by the intellectual disability diagnosis, maternal depression, and increased worrying. Finally, the researchers found that parents who were more satisfied with their child's transition experienced greater well-being than parents who were dissatisfied. These results demonstrate the importance of a successful transition to adulthood on the welfare of the entire family.

Complementing the parental perspective provided by Neece and colleagues, Forte, Jahoda, and Dagnan (2011) explored the worries that 26 young adults with intellectual disability experience as they transition to adulthood compared to 26 typically developing young adults (both groups: ages 17-20 years). All participants completed a semi-structured 'worry' interview, a measure of self-efficacy, a measure of anxiety, and a measure of intelligence.

Ways to Improve the Transition:

1. Ask school personnel how you can be more involved in the transition planning process.
2. Begin transition planning earlier to provide individuals more time to prepare for the transition to adulthood and parents more time to get involved with the transition planning process.
3. Implement a person-centered transition plan. Such a transition plan involves both the individual and the individual's close circle of support (e.g., family, friends, professionals, teachers) to create a plan individually tailored to the specific needs, concerns, and desires of that individual.
4. Identify key areas of worry for the young adults and begin intervention to alleviate some of these concerns and increase emotional resilience.
5. Work to reduce anxiety by talking through issues such as dependency, social exclusion, stigma, and fear of failure.

TAKE HOME TIPS FOR PARENTS

Forte, M., Jahoda, A., & Dagnan, D. (2011). An anxious time? Exploring the nature of worries experienced by young people with a mild to moderate intellectual disability as they make the transition to adulthood. *British Journal of Clinical Psychology, 50*, 398-411.

Neece, C.L., Kraemer, B.R., & Blacher, J. (2009). Transition satisfaction and family well being among parents of young adults with severe intellectual disability. *Intellectual and Developmental Disabilities, 47*, 31-43.

Wagner, M., Newman, L., Cameto, R., Garza, N., & Levine, P. (2005). After high school: A first look at the postschool experiences of youth with disabilities. *A Report from the National Longitudinal Transition Study-2 (NLTS2)*. Menlo Park, CA: SRI International.

REFERENCES USED IN ARTICLE

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UPCOMING EVENTS:

11th Annual Autism Conference: Incorporating Evidence Based Practice Into the Classroom: Practical Strategies for Every Student: Save the Date! Bryant Conference Center, March 2, 2012. Visit <http://autism.ua.edu> or call (205) 348-3000 for more information or to register.

Mississippi Department of Special Education- 2012 Building Partnerships...Working Together Conference: Jackson Convention Complex, Jackson, MS, March 5-6, 2012. Visit www.msccd.org for more information or to register.

P.U.R.E. Celebration by Zachariah's Way: night of worship and praise in honor of children with special needs, Samford University, Birmingham, AL, April 20, 2012. Visit www.pureministryproject.com for more information.

6th Annual Acoustic Soup: live music, soups, breads and desserts from Birmingham's most popular chefs and restaurants, all proceeds benefit VSA Alabama, Birmingham, AL, January 26, 2012. Visit www.vsaalabama.org for more information or to purchase tickets.

Florida Down Syndrome Conference: University of Central Florida, Orlando FL, February 24-25, 2012. Visit www.dsacf.org for more information or to register.

THINGS TO NOTE:

- Our website is up and running! Please check it out at www.uaidpr.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!
- If you know someone who would like to join the registry, please ask them to email or call us.
- Let us know if you would like copies of the articles referenced in this newsletter.
- Look for our next newsletter in Summer 2012!
- Allyson Phillips recently took over as Registry Coordinator for all of your family research needs! Jennifer Rhodes' last day with us was December 14, 2011. We are sad to see her go, but she will soon be an amazing social worker!

TRANSITIONING, CONTINUED

These researchers found significant qualitative differences in worries between individuals with intellectual disability and typically developing individuals. For example, the young adults with intellectual disability expressed concerns about being bullied, losing someone they are dependent upon, failing in life, and making and keeping friends. In contrast, the typically developing young adults worried most about getting a job, not having enough money, failing at an important task, and making the right decisions about their future choices. Additionally, individuals with intellectual disability ruminated more over their worries and found their worries to be more distressing than the typically developing individuals. By gaining insight into the specific worries of young adults with intellectual disability, this study allows for the improvement of intervention efforts aimed at increasing emotional resilience.

Taken together, these results help us understand the source of some of the added stress individuals and families experience during the transition to adulthood, and several steps were identified to make this period of transition less stressful and more successful. Further, by identifying the key worries for young adults with intellectual disability, better intervention services can be provided to improve coping mechanisms for handling these concerns.

Much more research is needed to better improve the transition planning process as well as the transition period itself. One current study will hopefully provide answers to many unanswered questions. This study is the National Longitudinal Transition Study-2 (see Wagner, Newman, Cameto, Garza, & Levine, 2005), which includes over 11,000 transition-age youth with intellectual disabilities. Through this study, researchers are hoping to better understand the factors associated with positive outcomes for youth transitioning out of high school, including academic achievements, postsecondary education participation, student involvement in transition planning, employment after high school, leisure activities, and social involvement. As results of this study become available, we will share the findings with you.

Thanks to Allyson Phillips for reporting on these studies.

UA IDPR

WINTER 2012

Looking for Activities to Stay Busy this Winter and Spring....

Alabama

PADS: Parents and Caretakers Night Out, Birmingham, Feb. 17, 2012

Exceptional Foundation: Annual Chili Cook-off, Birmingham, March 3, 2012

Mississippi

Bowling with the Gulf Coast Ally Cats (ages 17 & up): Saturday mornings, Gulfport, contact Mrs. Dean Oliver (228) 396-1656 for more information

Georgia

Baby & Child Expo: Atlanta, Fox Theatre, May 12, 2012

The Velveteen Rabbit- PJ's & Play: Atlanta, Fabrefaction Theatre Company, March 30, 2012

Florida

DSACF: Visit www.dsacf.org for a list of activities including support groups, sign and play, teens and teens groups, young adults groups, and Dads Appreciating Down Syndrome group

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!



tuscaloosa
alabama

PROMOTING RESEARCH ON INTELLECTUAL DISABILITY

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



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