

Visit our website at
www.uaaidpr.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,

Many of you participated in a study conducted by Dr. Gayle Graham Faught; 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!

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 peer victimization in individuals with Down syndrome. If you would like more information on this study, please let us know.

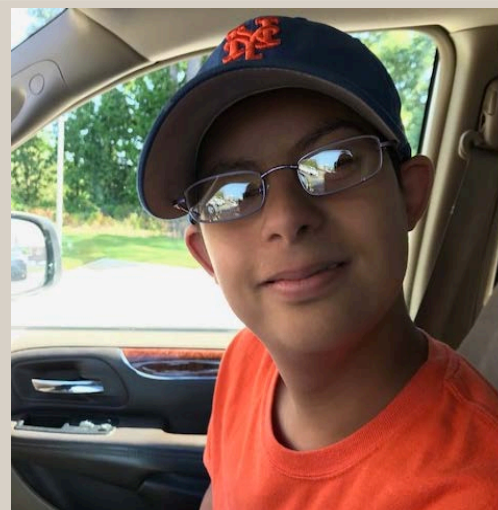
We also have a special contribution from Jenna Reardanz, a graduate student in the Conners Lab. Jenna's research focuses on peer victimization and she sat down with us to talk about this important topic.

The registry will also be seeking parents and adults interested in being part of an advisory board for the registry. The function of this board will be to provide feedback on issues related to the registry. If anyone is interested in this opportunity, please let me know.

All of this in the Summer 2017 newsletter!

Eric

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



SPOTLIGHT ON ISAIAH PALOS!

Isaiah is 14 years old and recently entered the 7th grade. He loves school and being with friends. He likes basketball, swimming, the beach, and taking vacations. Isaiah also loves music and enjoys listening to Kidz Bop!

WHATS INSIDE

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RESEARCH REVIEW: FT0GAYLE GRAHAM FAUGHT

Modeling the Relationships Among Sustained Attention, Short-Term Memory, and Language in Down Syndrome

Language can be a challenge for youth with Down syndrome (DS). Gayle's dissertation study sought to determine if reasons for this language difficulty in Down syndrome include sustained attention (the ability to maintain attention over time), and short-term memory (the temporary storage and retrieval of information in memory).

Gayle tested 37 participants (many from the registry - thank you all!) and found that sustained attention to auditory information (e.g., spoken language) predicted language *through* short-term memory of auditory information. In other words, youth with Down syndrome sustain attention to language, then crucially hold the attended information into short-term memory, to eventually learn language.

These findings hold potential implications for language therapy with youth with Down syndrome. Perhaps addressing auditory sustained attention in language therapy with youth with Down syndrome could improve outcomes, though this idea needs to be tested with additional research. From this research Gayle was able to obtain her PhD in Developmental Psychology!

TAKE-HOME FOR CAREGIVERS:

You may already be doing the things below without knowing it, but here are some tips:

1. Keep in mind- it may not be easy for your family member with DS to keep their attention on the conversation.
2. Before starting to speak with your family member with DS, make sure you have their attention.
3. Remember that it is common in DS for auditory short term memory to be short. Your family member may find it hard to process statements that are long and complex.

TAKE-HOME TIPS FOR PARENTS



Dr. Gayle Graham Faught completed her PhD this year and will be teaching full-time in the Psychology department at the University of Alabama this Fall.

UPCOMING REGISTRY-SUPPORTED STUDY:

Communication and the Social Experience of Adolescents with Down Syndrome

Little is known about the social experiences of adolescents with Down syndrome (DS). Jenna Reardanz, a graduate student in the Connors Lab, is conducting a study to see how language communication is related to middle schoolers' social experiences with peers, the way they deal with their emotions, and how they feel about themselves. The results of this study could potentially contribute to efforts to reduce negative social experiences, specifically the creation of school interventions.

This study, which will take between 1 ½ - 2 hours to complete, involves the middle schooler with DS talking with the research team about their social experiences and completing two tasks. One task involves telling a story based on a picture book while the other task asks participants how they would respond in certain social situations. In addition there are a few questionnaires for the parent/guardian to complete. This study will begin in the fall.

THINGS TO NOTE:

- Visit our website 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!
- We would 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 a new addition to our team, Ethan Lewis!

ETHAN LEWIS



Ethan Lewis is from Homewood, Alabama. He is majoring in psychology with a chemistry minor. Ethan's research interests are cognitive and social development in children and adolescents.



The UAIDPR has partnered with DS-Connect, a national Down syndrome registry sponsored by the Department of Health and Human Services that allows families to find providers in their area, explore trends in the overall health of people with Down syndrome, and connect with scientists who study Down syndrome. For more information visit <https://dsconnect.nih.gov/>

Does having an intellectual disability mean being a victim? – By Jenna Reardanz



“How do I keep my child safe?” This question is one that enters the mind of any parent/caregiver and hangs on for dear life. As babies become young children and enter school, peers are suddenly a large part of your child’s life. With the new joys that come with watching new friendships blossom, new worries often arise. Questions like *“will my child have friends?”* or *“will my child be bullied?”* often bounce around in parents’ heads. The teenage years do little to ease parents’ concerns; as we all know, the teen years can be very socially difficult. And when a child has intellectual disability these questions are often amplified. So, what can parents do to keep their child from being bullied? Well, first let’s look at what the research says.

Research about bullying among kids and teens with an intellectual disability is sparse. In fact, according to the PACER Center’s National Bullying Prevention Center, only 10 studies have been done in the U.S. that look at the link between bullying and Intellectual disabilities. What we know from this research is that those who have an intellectual disability are 2-3 times more likely to be bullied than their typically developing peers. Those with an intellectual disability are also more likely to have fewer friends and report lower satisfaction with the friendships they do have. Specific research for kids and teens with an Intellectual Disability shows us that bullying risk factors, like poor emotion regulation and communication ability, tend to be higher, potentially increasing their risk of being bullied. While this may seem bleak, life experiences show us that Intellectual Disabilities and being bullied are **not** synonymous. It is entirely possible for kids and teens with Intellectual Disabilities to have successful, satisfying social lives.

So, what does all this mean? The bottom line is that **a lot more research needs to be done before we can make any reliable conclusions.** But, there are some things that you, as a parent/caregiver, can do to help support healthy social development. 1) Be sure your child knows what is and isn’t okay for other kids to say and do. This may seem obvious, but it is important to make sure your child knows so they can report it if anything should happen. 2) Encourage your child to talk to you about their friends. This will allow you to help your child spot bullying and keep you in the loop. 3) Help your child know how they can make others more comfortable around them. For example, if your child tends to stand very close to others in conversation, remind them that taking a step back is a good idea. Don’t change who your child is, but don’t forget to remind them if they need it! 4) Help your child get and stay involved with activities they enjoy. This could be anything from choir, to sports, to volunteering. This can help your child be more comfortable around others and get to know them better. It will also help others get to know your child and see how great they are! 5) Stay as involved as you can with your child’s social life. This will likely be more difficult as your child gets older, but do what seems best for your child. After all, you know them better than anyone. Also remember that teachers and school staff are a good resource to help make sure your child isn’t being bullied at school. The first step to ending bullying is identifying if it is happening.

To summarize, **kids and teens with an intellectual disability may be more likely to be bullied, but the research is minimal.** We are currently working to start to fill in the gaps, but in the meantime, stay involved and present in your child’s life. **In the right atmosphere kids and teens with an intellectual disability can, and do, thrive socially.**

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FRI

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DSA Alabama Step Up for DS,
Hoover AL. 205-988-0810.

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MADSOG Buddy Walk, Montgomery AL.
montgomerybuddywalk@gmail.com

The EXPO: Roads to Possibilities. Davie, FL.
<http://www.theexpofl.com/>

Lowcountry DS Society Buddy Walk, Savannah
GA. <https://ldssga.org/>

NAMIWalks Georgia, Atlanta Georgia.
<http://www.dekcsb.org/>

FDSWF Buddy Walk, Tampa FL. 813-245-2782

08

DSAA Buddy Walk, Atlanta GA.
http://www.dsaatl.org/buddy_walk

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2017 Wiregrass Area Buddy Walk, Dothan AL.
334-718-3356

CVDSA Buddy Walk, Columbus GA.
<http://cvdsa.org/>

Upside of Downs Buddy Walk, Aiken GA.
csrabw@aikenupsideofdowns.org

CMDSS Buddy Walk, Pearl MS.
<http://cmdss.org/>

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21 United Buddy Walk, Oxford
MS. www.21united.org

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DS Society of Mobile County Buddy Walk,
Mobile AL. <http://www.dssmobile.org/>

Special Olympics Fall Games, Hattiesburg, MS.
601-856-7748

DSA of Central Florida Buddy Walk, Orlando FL.
407-478-5621.

Manasota BUDS Buddy Walk, Bradenton FL.
<https://www.manasotabuds.org/>

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Special Olympics Fall Games,
Hattiesburg, MS. 601-856-7748

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DSAT Buddy Walk, Tallahassee FL.
<http://dsatallahassee.com/>

The ARC of Volusia Buddy Walk, Deland FL.
<http://arcvolusia.org/>

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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!*

