

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 idl原因@ua.edu for more information.

STUDIES CURRENTLY NEEDING PARTICIPANTS Please contact the Registry for information!

Learning and Language Research Study

Dr. Fran Connors 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 intellectual disabilities. This study is enrolling participants ages 10-21 with intellectual disability and participants ages 4-5 who are typically developing.

Reading Skills in Down Syndrome

This is an on-going study being conducted by Dr. Susan Loveall and Andrew Tungate. Results of the study so far were reported in the last newsletter, but more participants are needed! This study is examining reading skills in individuals with Down syndrome through parent reports. Parents are asked to fill out two surveys about their child's reading skills and what types of reading activities are done in the home. Parents of individuals with Down syndrome of all ages are needed (birth through adult). Children do not have to be able to read for the parents to participate.

Physical Activity and Cognition in Down Syndrome

This study is being conducted by Andrew Tungate. He is examining the relationship between exercise and cognition in Down syndrome. Findings will help us understand if increased exercise could potentially improve cognitive functioning. This study is enrolling participants with Down syndrome aged 5-21 years.

Send us your Pictures! We would love to feature you in the next newsletter!



STYLISH ISABELLA- SHE ALWAYS HAS THE CUTEST OUTFIT!

Note from the Registry Coordinator:

Dear Registry Families,

I am sad to say that I will no longer be the Registry Coordinator after this semester. I have finished my Ph.D. and have accepted an Assistant Professor position at Ouachita Baptist University in Arkansas. I am very excited about this next adventure, but I will truly miss working with each of you! It has been an honor and a privilege. Your kindness and willingness to participate in the research studies makes our work possible. The love, support, and dedication that you give to your children is astounding and commendable. You guys are my heroes for never giving up when the times get tough and for continually striving to improve the lives of those with intellectual and developmental disabilities. I have learned so much for you, and I will be taking this knowledge with me as I leave The University of Alabama. I promise that the Registry is being left in the capable hands of our team of researchers. They are ready to get to know you and to continue the research on intellectual disability. Thanks, again, for making these past two years so enjoyable!

Sincerely,
Allyson Phillips

RESEARCH REVIEW: PARENTING CHILDREN WITH DOWN SYNDROME

Many of you participated in a research study conducted by one of our graduate students, Dr. Allyson Phillips. The study, *Parenting Children with Down Syndrome*, examined parenting styles and dimensions in mothers of children with Down syndrome compared to mothers of typically developing children. Effective parenting is vital for a child's intellectual, physical, social, and emotional development, and not all parenting techniques are equal in terms of their effectiveness in raising a healthy, well-adjusted child. While much work has been conducted on parenting typically developing children, little work has examined parenting children with Down syndrome.

There are three primary parenting styles—authoritative, authoritarian, and permissive. Authoritative parents stress parental control through the use of warm, responsive parenting. They provide their child with explanations, treat their child as an individual, and work to promote their child's autonomy. Authoritarian parents emphasize parental control by demanding obedience and frequently using harsh and forceful punishment. They provide their children with little warmth, affection, or nurturance. Parents who utilize permissive parenting have no parental control and, while they are warm, they place few demands on their children. They completely accept their children's desires and actions and require little of their children in terms of household responsibility and obedient behavior. Authoritative parenting has been repeatedly associated with the most positive child outcomes, while authoritarian and permissive parenting are associated with more negative child outcomes.

There are six primary parenting dimensions—warmth, rejection, structure, chaos, autonomy support, and coercion. Warmth is associated with love, affection, caring, enjoyment, appreciation, and emotional support. Rejection is associated with hostility, aversion, harshness, over-reactivity, irritability, critical evaluations, and disapproval. Parents who utilize structure provide a clear explanation of rules and disciplinary action, follow-through when discipline is necessary, and predictable routines and organization within the household and daily life. Chaos is linked to disorganization, environmental confusion, and inconsistency and unpredictability in rules and discipline. Autonomy support promotes independence, supports the child in the exploration of personal preferences and opinions, allows the

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What You Can Do To Help:

1. Work to establish daily routines with your child such as bedtime routines and dinner routines.
2. Explain to your child what the household rules are and what the consequences are for breaking these rules.
3. Follow through with appropriate disciplinary action when rules are broken. Do not allow your child to continually get away with bad behavior.
4. Recognize that stress has negative consequences to your own health and to your relationship with your child. Try to decrease the stress in your life.

TAKE HOME TIPS FOR PARENTS



DR. ALLYSON PHILLIPS
WITH DR. FRAN CONNORS

UPCOMING EVENTS:

Auburn Heights Annual Easter Celebration: 4207 Auburn Rd., Phenix City, AL, April 12th, 10:00 – 1:00. Easter egg hunts for ages 0 – 12, bunny photos, games, prizes, face painting, story times, and more. Free event!

Visit www.easteregg huntsandevents.org for more information.

Earth Day Kids Fest: Chattahoochee Nature Center, Roswell, GA, April 12th, 10:00 – 3:00. Be an Eco-Hero! Farmer Jason will have you rockin' out to songs and the Eco-Village will introduce you to local environmental groups and hands-on activities such as up-close wildlife encounters, canoeing around Beaver pond, and eco-crafts.

Visit www.atlantaplanit.com for more information.

Spring Pilgrimage: Natchez, MS, March 8th – April 8th. Twenty-nine antebellum mansions open their doors to visitors. Your guides are costumed family friends and descendants of the original owners. Each house is unique with 18th and 19th century furnishings, porcelain, silver, clothing, tools, documents and diaries.

Visit www.natchezpilgrimage.com for more information.

JestFest!: Gainesville, FL, Bo Diddley Community Plaza, April 5th, 12th, 19th, and 26th. From the Flying Wallenda's high wire, Cirque-style family of acrobats to a sword swallower, enjoy family-friendly entertainment.

Visit www.gvlculturalaffairs.org for more information.

THINGS TO NOTE:

- Visit our website is 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 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.
- We will be contacting you shortly to update your contact information. Be expecting an email or phone call in the next couple of months.

PARENTING, CONTINUED

child to freely express ideas and actions, and encourages the child's contribution in decisions and problem solving. Finally, coercive parents demand obedience and implement restrictive, over-controlling parenting through the use of harsh punishment. They also attempt to change or control how their child thinks, feels, or behaves and will talk to their child in a derogatory manner (e.g., telling the child that he/she is dumb or stupid). Warmth, structure, and autonomy support are associated with positive child outcomes, while rejection, chaos, and coercion are associated with negative child outcomes.

In the current study, 35 mothers of children with Down syndrome and 47 mothers of typically developing children (age 5-12) participated. The mothers completed nine questionnaires asking about the way in which they parent their child, their child's cognitive and behavioral abilities, their own well-being, and the expectations and fears they have in relation to their child.

The researchers found that mothers of children with Down syndrome use an authoritative parenting style less and a permissive parenting style more than mothers of typically developing children. Additionally, they found that mothers of children with Down syndrome provided their children with less structure but more chaos than mothers of typically developing children. However, mothers from both groups used similarly high levels of warmth and autonomy support and similarly low levels of rejection and coercion. Further, the differences that they found on parenting styles and dimensions no longer existed when they accounted for differences in parental stress.

Parents of children with Down syndrome experience far greater levels of stress than parents of typically developing children. This increased stress might be due to the children's increased behavioral problems, increased health-related problems, or decreased cognitive abilities. Parents also experience greater care-giving demands, increased financial burdens, more issues associated with advocacy, limited formal and informal support, and decreased feelings of competency.

The results suggest that mothers of children with Down syndrome are overall using similar parenting methods as mothers of typically developing children. Differences that do exist between the mothers is most likely due to the increased levels of parental stress for mothers of children with Down syndrome. As such, parenting interventions for parents of children with Down syndrome should either be focused on reducing parental stress in an effort to improve parenting techniques or on educating parents on how to utilize positive parenting techniques despite their stressful life circumstances.

UA IDPR

SPRING 2014

Look Here for Upcoming Events in your Area:

Alabama

Golf for Down Syndrome:
June 2nd, 10:30-6:00
Inverness Country Club
www.downsyndromealabam.org

Exceptional Foundation Summer
Camps: Birmingham
(205) 870-0776

Georgia

AADD Family Support Spring
Workshops
www.aadd.org

DSAA iCan Bike Camp: June 23-27th
Northview High School in Duluth
www.dsaatl.org

Mississippi

Mississippi disability Megaconference:
June 12-13th, Jackson Marriott
www.mspti.org

Gaits to Success, Therapeutic
Horsemanship Center
(228) 255-5368

Florida

DSACF: Down to Party and Auction,
May 9th, 7:00
www.dsacf.org

DSAJ Charity Golf Classic: April 25th,
Amelia National Golf Club
www.dsaj.org

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

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touching lives