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## Research Newsletter

Dear Community Partners,

Welcome to another edition of the Developmental Pediatrics/JFK Partners Research Newsletter!

Our last issue was published in Spring 2020, just as COVID-19 was taking hold in our country and worldwide. At that time, many of our research projects temporarily paused recruitment to maintain the safety of our research participants and faculty. We are pleased to let you know that at this time, a number of our research projects have been able to restart recruitment efforts! (see recruitment section in this newsletter for more information). Because COVID-19 continues to have a significant impact on our community, we have updated our COVID-19 resources section, so check it out!

### [SPOTLIGHT!](#)

In this issue, we are highlighting the work of Audrey Blakeley-Smith, Ph.D. Associate Professor of Psychiatry and Pediatrics, and Licensed Clinical Psychologist at JFK Partners and Developmental Pediatrics. Since her arrival at JFK Partners 16 years ago, Dr. Blakeley-Smith has become an active researcher in the treatment of anxiety in youth with ASD. She has recently spearheaded an effort to adapt the Facing Your Fears program for teens with ASD and intellectual disability.

### [RESEARCH UPDATES](#)

Check out the research update section for current updates on the research projects that are ongoing or recently completed with Developmental Pediatrics/JFK Partners.

### [RECENT PUBLICATIONS](#)

We have included a list of recent publications at the end of this newsletter.

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Don't miss our Recruitment Section where we list research projects that are actively recruiting individuals for participation.

## **NEW SECTION – [ARTIST'S CORNER!](#)**

In this new section of the newsletter, we are showcasing the creative works of people in our community. In this issue, we have published a poem written by Edwin Austgen, age 12.

## **FEEDBACK**

We would appreciate any feedback you have for us about this newsletter, as well as topics you are interested in hearing about in future editions. We are also interested in creative works of art for our Artist's Corner! Please share your submissions and any other general [feedback here](#).

Warmly,

*Judy Reaven, PhD*

Director of Research, JFK Partners/Developmental Pediatrics

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### **COVID-19 Resources: Supporting Children and Families Returning to School**

Developmental Pediatrics and JFK Partners faculty and fellows have updated their COVID-19 Resources, first published at the beginning the pandemic to focus on resources for children returning to school. Click on the gold button above for a copy.

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## **[SPOTLIGHT](#)**



Audrey Blakeley-Smith, PhD  
Licensed Clinical Psychologist  
Associate Professor of Psychiatry and Pediatrics  
Psychology Internship Director  
University of Colorado Anschutz Medical Campus

### **How did you become interested in research?**

After college, I sought training at an institution known for its dual commitment to research and care: Kennedy Krieger Institute. On the Neurobehavioral Unit, I worked with people with developmental disabilities and severe self-injury. I learned the significant role assessment plays in determining the function of behavior and that effective design of intervention requires careful consideration of these maintaining variables. More importantly, however, I was moved to commit my professional career to collaboration with and support of people with developmental disabilities. I went on to graduate school and completed a Ph.D. in clinical psychology under the mentorship of Dr. Ted Carr at Stony Brook University. Dr. Carr was a leader in the field of positive behavioral supports. He taught me the important role of “truth-seeking” in empirical research. When you focus on direct assessment, careful manipulation of independent variables, and thoughtful measurement, you can obtain results that are empirically sound, and ideally life-changing. The results, he cautioned, may not always be what you expect or want, but the bad data may inform your work more than the good. With this in mind, I moved to Colorado in 2004 where I completed my clinical internship year and then a postdoctoral fellowship at JFK Partners.

included me in their program of research: examining the use of CBT (e.g., Facing Your Fears) for anxiety in children with ASD. Through Dr. Reaven and Hepburn's mentorship and later partnership, I have been thrilled to be involved in a program of research that has served to strengthen parents' abilities to support their children's use of CBT, and capitalize on children's resiliency and desire to be brave.

### **Current project and practical implications?**

We are now examining an adaptation of Facing Your Fears for adolescents with ASD, intellectual disability (ID), and anxiety. This program may be one of our most important adaptations to date. This population faces many barriers to mental health treatment, the most significant of which is the lack of evidence-based, manualized interventions. Carefully examining necessary adaptations for CBT and testing its effectiveness will take us one step closer to developing an evidence-based intervention for this underserved population. Further, treating anxiety in adolescence will help build important, pre-requisite coping skills that may aid a positive transition to adulthood.



## Research Update

Facing Your Fears in Schools: An Implementation Study to Manage Anxiety in Underserved Students with ASD or other Social/Communication Challenges

PI: Judy Reaven, PhD

### **What is School-Based Facing Your Fears?**

Facing Your Fears is an evidence-based group cognitive behavior therapy (CBT) program for children 8-14 with ASD and anxiety. The school-based version of FYF (FYF-SB) is a 12 week, 40 minutes/week curriculum delivered by inter-disciplinary school teams to students with ASD or other social/ communication challenges and anxiety during the school team. FYF-SB helps students manage interfering anxiety symptoms and improve emotion regulation.

Three public school districts in Colorado participated in the Facing Your Fears school-based research project: Cherry Creek School District, Denver Public Schools, and Littleton Public Schools. Thirty-four interdisciplinary school providers from 11 elementary and middle schools, participated across three districts. Twenty-four students completed FYF-SB and student and parent report indicated that significant reductions in anxiety occurred following participation in FYF-SB.

### **Phase 2: (2019-2020) (Recently Completed)**

A Train-the-Trainer model was implemented across districts to train 77 providers across an additional 27 school teams. Eight-one students enrolled in FYF-SB across schools in a randomized controlled trial. Preliminary outcomes suggested that school providers found FYF-SB easy to understand and put into practice and that FYF-SB enhanced their ability to manage their students' anxiety. Students indicated that they enjoyed participating in FYF-SB and reported less worry and anxiety following the group. Initial data analyses indicated that according to both parent and student report, significant reductions were noted in anxiety (e.g., separation and social anxiety) for students participating in FYF-SB compared to students assigned to treatment-as-usual.

### **Implications:**

These initial results are encouraging and indicate that training interdisciplinary school providers to deliver FYF-SB can provide access to evidence-based mental health care for many students with ASD or other social/communication challenges in school settings. Providing FYF-SB in schools has the potential to decrease health disparities to the students, directly and indirectly, involved in the program.

COMIRB Protocol: #18-0114

### **Funding Source:**

Health Resources and Services Administration (HRSA) Award #R41MC31075 2017-2020  
Participating School Districts: Denver Public Schools Cherry Creek School District Littleton Public Schools. For more information about Facing Your Fears contact Dr. Judy Reaven directly: [judy.reaven@cuanschutz.edu](mailto:judy.reaven@cuanschutz.edu).

**Check out the Facing Your Fears Video Series**

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Photo attribution: Children in School Classroom (Pixlr)

## Research Update

### Advancing Autism Research in Diverse Populations: Anxiety in the Schools

Nuri Reyes, PhD

In an off shoot of the Facing Your Fears in Schools project, our goal was to understand parents' and school providers' views regarding anxiety within school settings. Fourteen focus groups were convened with parents, who had at least one child with ASD and co-occurring anxiety, and with school providers (e.g., special education teachers, speech and language pathologists, school psychologists).

During these groups, parents and school provider often discussed the following topics: 1) Anxious behaviors in youth with ASD at school; 2) Triggers of anxiety in school settings; 3) Process of identifying/assessing anxiety in schools; 4) Children whose anxiety is missed and why it is missed; and 5) Strategies to improve anxiety identification at school.

Findings from this present study suggest that youth with ASD tend to experience anxiety within school settings and schools vary in the assessment tools to identify measure anxiety. Also, a portion of children with ASD who experience anxiety are not identified, which highlight the challenges identifying anxiety in diverse youth with ASD. Parents and school providers offered strategies to support to knowledge about anxiety in youth with ASD and to support families decrease mental health stigma.

Reyes, N.M., Pickard, K., Tanda, T., Morris, M., & Reaven, J. (Submitted). Identifying and understanding anxiety in youth with ASD: Parent and school provider perspectives on anxiety within public school settings.

#### Funding Source:

Public Schools. For more information about Facing Your Fears contact Dr. Judy Reaven directly: [judy.reaven@cuanschutz.edu](mailto:judy.reaven@cuanschutz.edu).



Photo by Blaise Vonlanthen on Unsplash

## Research Update

### Emotion Regulation, Dysregulation, and Mental Health in ASD

Nuri Reyes, PhD

While emotion regulation is described as our ability to manage our emotional states, emotionality is described as our innate tendency to respond to emotionally charged events. Having good emotion regulation skills helps us to manage increased emotionality. Recent research indicates that having optimal emotion regulation skills is often helpful when dealing mental health problems. This might also be the case in youth with ASD.

In a recent study, we found that children with ASD with increased emotionality were more likely experience behavior/emotional difficulties, and those with better emotion regulation skills were more likely to have increased social skills. Given that children with ASD often struggle with social skills, and they are often at risk for mental health problems, fostering emotion regulation skills might be helpful for this population.

Dunsmore, J. C., Booker, J. A., & Ollendick, T. H. (2013). Parental emotion coaching and child emotion regulation as protective factors for children with oppositional defiant disorder. *Social Development*, 22(3), 444-466.

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anxiety disorders. *Clinical Child and Family Psychology Review*, 10(3), 275-293.

Reyes, N.M., Factor, R., & Scarpa-Friedman, A. (In Press). Emotion regulation, emotionality, and expression of emotions: A link between social skills, behavior, and emotion problems in children with ASD and their peers. *Research in Developmental Disabilities*, 106. 1-9.

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## Association of University Centers on Disabilities (AUCD) Launches Children's Mental Health Champions

Judy Reaven, Ph.D. was selected as one of six and will represent the state of Colorado as a Children's Mental Health Champion. Five other Champions will represent the states of California, Kentucky, New Mexico, Virginia and Washington, D.C. These Champions will develop and test strategies for building partnerships to promote identification, screening, referral and intervention for children with ASD or other developmental disabilities who may need services to address co-occurring psychiatric symptoms and/or problem behavior. AUCD is a national, nonprofit network of university-based centers and programs in every state and territory working to advance policy and practice for people living with disabilities and their families. JFK Partners is a University Center for Excellence in Developmental Disabilities (UCEDD) and is part of the AUCD network.

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## Survey

Improving the Recognition of Co-Occurring  
Mental Health Symptoms in Children and Adolescents  
with Autism Spectrum Disorder

The purpose of this study is to provide information that can help inform an effort by JFK Partners to increase awareness of the co-occurrence of mental health conditions in children and adolescents with ASD. Specifically, we hope to increase early screening and identification of mental health conditions in youth with ASD in the State of Colorado, as well as increase the capacity of providers to recognize these symptoms and refer for appropriate interventions.

If you join the study, you will be asked to fill out a 10-15 minutes survey that may provide information that can help to increase awareness of mental health conditions in children and adolescents with ASD.



To begin, please click on the below link:

<https://redcap.link/im0190xc>



Sandra L. Friedman, MD, MPH, Developmental Pediatrics Section Head and Director of JFK Partners has been working on several DBPNet projects.

[sandra.friedman@childrenscolorado.org](mailto:sandra.friedman@childrenscolorado.org)

### **Preschool ADHD and Telephone Medication Management at DBPNet Sites**

Our objective is to understand DBPs' use of clinic versus telephone encounters for preschool ADHD medication management. Understanding the use of telephone encounters in developmental-behavioral pediatrics (DBP) for pharmacologic management of ADHD in preschoolers may inform ADHD care.

DBP investigators within Developmental-Behavioral Pediatrics Network (DBPNet) abstracted data from medical records of 504 children age < 72 months treated for ADHD with medication by a DBP clinician between 1/1/2013-7/1/2017 across 7 sites. We abstracted data about medication treatment episodes (defined as start and end/change of a specific type, dose, and frequency of ADHD medication) and encounter type (clinic versus telephone). We present descriptive statistics related to encounter types and chi-square analyses to compare frequencies across reasons for the end of treatment episode and across sites.

The study included 504 participants with a total of 1,738 treatment episodes. The initial medication was started via a clinic encounter 85.9% of the time and via telephone encounters 14.1% of the time. When evaluating reasons for end of treatment episode, decreases in dose/frequency of medication were less common for clinic versus telephone encounters (27% vs 73%;  $p < 0.001$ ) and adding an additional medication was more common at clinic versus telephone encounters (65% vs 35%;  $p < 0.001$ ). Sites varied significantly in frequency of telephone encounters, ranging from 16.9% - 68.5% (mean 45.6%).

Telephone encounters were used for pharmacologic management of ADHD in preschoolers to varying degrees across 7 DBP sites. These findings suggest that telephone management may serve an important role in ADHD care.

### **Adverse Effects of Methylphenidate and Guanfacine in Preschoolers with ADHD: A DBPNet Study**

The purpose of this study is to compare the type and frequency of adverse effects associated with methylphenidate and guanfacine used in the treatment of preschoolers with ADHD.

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Developmental and Behavioral Pediatrics Research Network. Subjects were children age < 72 months treated by DBPs with a medication for ADHD from 1/1/2013 through 7/1/2017. For this study, a “treatment interval” was defined as the time from the initiation of treatment until that class of medication (methylphenidate, amphetamine, guanfacine, or clonidine) was either stopped, another medication was added, or the child turned 6 years of age. We abstracted data about age at initial medication treatment; type of medication used; and any adverse effects that were reported at in-person visits or on telephone calls during the first treatment interval. Amphetamine and clonidine were excluded due to low receipt (<10 and 2%, respectively) at initial treatment. X2 or Fisher exact test was used to compare proportions of adverse effects associated with methylphenidate or guanfacine.

We abstracted data from records of 504 preschoolers with ADHD who were treated with medication. Mean age of subjects was 59.7 months at initial ADHD treatment. Methylphenidate was the initial medication prescribed to 289 (57%) and guanfacine to 159 (31%) subjects. Methylphenidate had significantly greater rates of most adverse effects except for headache and daytime sleepiness, which were significantly more frequent with guanfacine. AEs occurring in less than 1% of subjects for both medications are not reported in the table. In general, adverse effects were more common with methylphenidate than guanfacine and occurred at similar rates to those described in the Preschool ADHD Treatment Study. Side effect profiles should inform clinical decision-making in medical treatment of preschoolers with ADHD.

### **Role of the Autism Diagnostic Observation Schedule in the Diagnosis of Autism by Developmental-Behavioral Pediatricians COMIRB#: 19-0382**

The goal of the present study was twofold: (a) to identify levels of consistency in ASD diagnosis over time and (b) predict stability of diagnostic decision-making using person and clinician characteristics.

Participants were 351 children who were undertaken ASD diagnoses across two time points. The diagnoses were offered by 44 clinicians who were nested within 8 sites from the U.S. and Europe. Besides clinician diagnoses, measures for cognition; language; adaptive skills were obtained. Demographic variables for the child involved gender, age, race, ethnicity, and presence of insurance. For the clinicians the respective estimates were gender, age, experience with neurodevelopmental disabilities, years past training, percentage of effort in the ASD population, generalized use of the ADOS

Results currently are preliminary although point to the ability of developmental-behavioral pediatricians to accurately identify children with ASD even before ADOS testing is performed.

[Read more about DBPNet Research](#)

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## Research Update

CASCADE Study: Cannabidiol Study in Children with Autism Spectrum Disorder  
A study of Cannabidiol (CBD) for treatment of Irritability/Aggression  
and Anxiety in Children with Autism Spectrum Disorder  
Principal Investigator: Nicole Tartaglia, MD, MS  
Co-Investigators: Ann Reynolds, MD, Sandra Friedman, MD, Elise Sannar, MD,  
Emily Werner, PhD, Judy Reaven, PhD

This study is designed to evaluate the effects of Cannabidiol (CBD) in children and adolescents age 5-17 with Autism Spectrum Disorder to determine if there are benefits or risks to symptoms of irritability, aggressive behavior, anxiety, social interactions, repetitive behaviors, and sleep compared to placebo.

The study will also evaluate safety and side effects of CBD in children with ASD. CBD is a chemical from the Cannabis (marijuana) plant that acts on receptors in the brain and throughout the body, but does not cause the same psychoactive effects of THC. The study medication is an FDA-approved liquid formulation of CBD derived from the cannabis plant that will be dosed based on the weight of the child and has a strawberry flavor.

Study participants will have 8-9 visits over a 27-29 week period. All participants will receive treatment with CBD for at least 12 weeks of the study period, with some participants receiving it for the entire study period.

This three-year study is sponsored by the Colorado Department of Health and Environment. If you are interested in more information please email your name and contact information to [CBDinAutismStudy@childrenscolorado.org](mailto:CBDinAutismStudy@childrenscolorado.org) or call Nana Welnick at 720-777-8608.

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## Research Update

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Principal Investigator: Cordelia Robinson Rosenberg, PhD, RN  
[Colorado.SEED@ucdenver.edu](mailto:Colorado.SEED@ucdenver.edu)  
303-724-7638

JFK Partners is in the third phase of the national SEED study, which is funded by the Centers for Disease Control (CDC). SEED is one of the largest epidemiological studies to date that is designed to compare children with autism spectrum disorder (ASD) and other developmental disabilities to children without these conditions. SEED 3 will help identify factors that might put children at risk for ASD and help improve services and treatments for children with ASD.

The research goals for SEED 3 include learning about:

- Physical and behavioral characteristics of children with ASD, children with other developmental disabilities, and children without a developmental delay or disability. We want to learn more about why people with and without ASD are the way they are—how they behave, grow, think, and interact with the world around them.
- We are interested in learning more about the health conditions and disorders that might affect children with and without ASD. SEED 3 provides an opportunity to compare health conditions and health-related issues such as sleeping and eating patterns.
- We hope that SEED 3 will give us a better idea which of the many possible risk factors that we will be evaluating seem to be associated with or related to ASD. The risk factors may be related to genes, health conditions, experiences of the mother during pregnancy, and the health and development of the child during infancy and the first few years of life.

SEED 3 is no longer enrolling new subjects. You can visit the Colorado SEED Study at [www.jfkpartners.com](http://www.jfkpartners.com) under Research.

Funding: CDC, National Center for Birth Defects and Developmental Disabilities, #5U01DD00120 (2016-2021).

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# FORWARD

FRAGILE X ONLINE REGISTRY WITH  
ACCESSIBLE RESEARCH DATABASE

## Research Update

## Fragile X Syndrome FORWARD Project

Fragile X syndrome (FXS) is a genetic disorder associated with increased rates of intellectual disability and Autism Spectrum Disorder. [The Denver Fragile X Clinic at Children's Hospital Colorado](#) is part of a national network of clinics working with the National Fragile X Foundation on a project funded by the CDC called the [FORWARD Registry and Database](#).

The goal of the FORWARD project is to collect data on a large, national group of children and adults with FXS to better understand their medical features, developmental features, medications, therapies, behaviors and overall quality of life across the lifespan. Recently, the Denver team worked on a project to describe the medical problems in the Fragile X population in the largest group of patients with Fragile X ever analyzed to date!

Here are some highlights from our analysis of over 1,300 patients with Fragile X from across the country:

- Recurrent ear infections occurred in 47% and were more common in males. Almost 40% of children with FXS received one set of ear tubes and 24% received multiple sets in their lifetime. Therefore, if a child with FXS has a fever or respiratory symptoms, it is important to consider having his/ her ears checked for an ear infection. Pressure equalizer tubes ("ear tubes") and a hearing evaluation should also be considered.
- About 15% of FXS individuals had past or present strabismus (misalignment of the eyes, also sometimes called "lazy eye"), which is higher than the 4% present in the general population. If strabismus is suspected, an eye doctor should assess for this because it can affect vision development.

This ongoing research enables us to continue to learn more about the medical care needed for patients with FXS, both in childhood and adulthood. This information will be used to update the National Fragile X Consensus Document on Physical Problems in Fragile X Syndrome, which contains guidelines on medical care so families and medical providers engage in evidence-based screenings and medical treatments. Other projects from the FORWARD database will also continue to examine topics related to seizures, autism, behavior, and therapies.

Denver Fragile X Clinic Team Members: Nicole Tartaglia, MD, Sara Williams, MD, Susan Howell, MS, CGC, and Karen Regan, RN. COMIRB#: 08-0735

Contact information: Karen Regan RN, Research Assistant, Vm: 720-777-8375,  
[Karen.Regan@childrenscolorado.org](mailto:Karen.Regan@childrenscolorado.org)

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Photo by Thomas Park at Unsplash

## Research Update

Determining the profiles of children with school difficulties  
by analyzing current practices of screening  
for Learning Disabilities  
at the Child Health Clinic at Children's Hospital Of Colorado

By Shanmuga Puji Jonnalagadda MD,  
Richard Boada PhD, Richard Boles PhD,  
Sandra Friedman MD MPH, Ayelet Talmi, PhD.  
COMIRB # 19-2929

This is a Developmental-Behavioral Pediatrics (DBP) Fellowship scholarly project that was developed from Dr. Shanmuga Puji Jonnalagadda's research interest in studying learning disabilities. Regular screening can improve early recognition and intervention of children at risk for Learning Disabilities (LDs).

Currently, signs of school distress are identified in the primary care setting when there are presenting concerns or through general developmental screenings. It is unclear if current screening practices are sufficient.

We are conducting a retrospective data analysis and chart review of 4997 unique patients, ages 6 to 17 years from January to December 2018 that were seen at the Child Health Clinic at Children's Hospital Colorado. Visits where parents answered affirmatively to a single question about school difficulties on the clinic-specific psychosocial screener were selected. Aims of the study are to (1) characterize the children who endorse a school concern, (2) identify if and how many these children were diagnosed with LD by reviewing the medical records and (3) determine if a plan of action was documented in addressing

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Preliminary results have shown that 6% of those given a psychosocial screener endorsed a school concern. We found that those with school concerns were 6 times more likely to also endorse financial stress, worrying about food insecurity and food running out when compared to all other families screened. We hope to further understand this population of families and children as we continue to examine all of our objectives.

Please contact Shanmuga “Puji” Jonnalagadda for more information:  
[shanmuga.jonnalagadda@childrenscolorado.org](mailto:shanmuga.jonnalagadda@childrenscolorado.org)

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## Research Update

Prevalence, Treated Prevalence, and Co-occurrence of Internalizing, Externalizing, and Tic Disorders in Colorado School-aged Youth (PLAY-Colorado)  
COMIRB # 14-0007  
PI: Lorraine F. Kubicek, Ph.D., IMH-E (Mentor-Research Faculty)

The specific aims of this study were to adapt and test an existing two-stage methodology to assess the prevalence, treated prevalence, and co-occurrence of internalizing, externalizing, and tic disorders in Colorado school-aged youth (ages 5-17 years). In the first stage, 858 teachers screened 4,183 students. In the second stage, 230 parents completed a diagnostic interview for a subsample of this population of students (half who screened high, half who screened low). Data analysis and manuscript preparation, in collaboration and consultation with the CDC, are ongoing.

Contact information: Lorraine F. Kubicek, Ph.D., IMH-E (Mentor-Research Faculty), 303-724-5953 (office); 303-919-0793 (cell) or [Lorraine.Kubicek@cuanschutz.edu](mailto:Lorraine.Kubicek@cuanschutz.edu).

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## Research Update

Improving Outcomes Using Augmentative and Alternative Communication for Children Who are Deaf or Hard of Hearing A Technology-Assisted Language Intervention Randomized Controlled Trial

This study is a multi-site study exploring different methods of language intervention that might help improve language skills of children who are deaf/hard of hearing. Children will be randomly assigned to either a treatment as usual language intervention group, or a group using technology (i.e., Augmentative and Alternative Communication, AAC) to facilitate language intervention.

Children who are between the ages of 3-10 years old who have a permanent bilateral hearing loss and who have language delay OR a gap between their language skills and their nonverbal ability may be appropriate for the study. All children will

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weeks of weekly speech/language therapy (1 hour/week). Following participation in the study, those who were not assigned to the technology group may choose to participate in the intervention.

This study is funded by NIH. COMIRB 19-2717. Cincinnati Children's Hospital sIRB 2016-6954. PI: Jareen Meinzen-Derr, PhD, MPH, FACE; Local PI: Deborah Mood, Ph.D. [TALI@ucdenver.edu](mailto:TALI@ucdenver.edu) Dates: 4/1/2020-3/31/2025



## Research Update

Measuring Hearing  
in Children with Developmental Differences

PI: Angela Yarnell Bonino, Ph.D., CCC-A

Nearly 40% of children with hearing loss have a secondary disability, yet audiologists lack the appropriate behavioral assessment procedures to measure hearing in children with diverse or complex developmental profiles.

The goal of this line of research is to improve hearing health care for children with developmental disabilities by transforming behavioral hearing testing methods. Our two specific aims are: (1) identify gaps in the current state of clinical assessment practices for children with developmental disabilities; and (2) identify factors that influence behavioral threshold accuracy. Under the first aim, big data analytics with a publicly-available database are being used to assess the current clinical situation.

For the second aim, using a novel observer-based psychoacoustics procedure, we are evaluating methodological and child factors that are expected to affect behavioral data from 1.5- to 5-year-old children with different developmental status (Autism Spectrum Disorder, Down syndrome, or typical development).

This research is significant because it will provide strong scientific evidence for modifying current clinical procedures for children with developmental disabilities and for developing



If you are interested in learning more, please email [childhear@colorado.edu](mailto:childhear@colorado.edu) or call 303-735-6252. CU Boulder IRB #: 16-0639

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## Efficacy of Crisis Plans for Individuals with Neurodevelopmental Disabilities and Behavioral Dual Diagnoses

This trial has been discontinued due to lack of enrollment and lack of personnel. The Crisis plan material are still available and people are encouraged to use them.

Contact Information: [Cordelia.Rosenberg@cuanschutz.edu](mailto:Cordelia.Rosenberg@cuanschutz.edu)

COMIRB#: 17-0845

PI: Cordelia Rosenberg

**Check out Crisis Planning Materials**

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More Than The Birds And The Bees - Birds And Bees Cartoon free from [www.clipartmax.com](http://www.clipartmax.com)

## New Clinical Program

**The Birds & the Bees: A Parent Group Curriculum**

**for Supporting Children and Teens**

**on the Autism Spectrum Through Puberty and Beyond**

The Birds & the Bees group is a new parent curriculum developed by Lindsey DeVries,

growing up.

This program is designed to meet the unique needs of children and adolescents with ASD that is often lacking from traditional sexual education programs and prepare parents for engaging in difficult conversations with their children. In particular, this group seeks to provide information and strategies specific for individuals with ASD for parents and caregivers about sexual health, puberty, dating, gender identity, social safety, and other common concerns that arise in adolescence. The parent-only group will meet for 8-weeks via telehealth.

Recruitment for the group is ongoing through the department of Developmental Pediatrics. The group is intended for parents of children with ASD between the ages of 12 and 18. Participants will be matched on the cognitive abilities and sex of their child. Content may vary based on parent and child needs. The first group is anticipated to begin in October 2020 and data collection is expected to begin shortly thereafter.

This is a clinical program we hope will turn into a research project in the future.

Please contact Developmental Pediatrics (720-777-6630) or Lindsey DeVries ([lindsey.devries@childrenscolorado.org](mailto:lindsey.devries@childrenscolorado.org)) for more information.



## Supporting Children of the Opioid Epidemic

Lorraine F. Kubicek, Ph.D., IMH-E (Mentor-Research Faculty)

Project SCOPE is a national initiative to train interdisciplinary teams in targeted states on emerging knowledge and evidence-based practices in screening, monitoring, and interdisciplinary care for children and families diagnosed with Neonatal Abstinence Syndrome (NAS), Neonatal Opioid Withdrawal Syndrome (NOWS), or who are suspected of being impacted by opioid use, trauma, or related exposure.

Project SCOPE will build on the ECHO virtual training model and is intended to improve outcomes by linking research to practical application in local communities, providing opportunities to share knowledge and findings with national networks and federal agencies, and providing recommendations for future interventions. This training initiative is supported by [the Wyoming Institute for Disabilities](#), [the Nisonger Center at The Ohio State](#)

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Our HUB team, which includes Anne Auld ([Illuminate Colorado](#)) and Abigail Angulo, Melissa Argenti, Renee Charlifue-Smith, Dina Johnson, and Lorraine Kubicek (PI), completed their virtual immersion training for SCOPE in July. The HUB team is responsible for designing the curriculum, identifying expert presenters, and overseeing the implementation of the project. The team is planning to roll out the first implementation of the training in January 2021.

To know more about the project: Lorraine F. Kubicek, Ph.D., IMH-E (Mentor-Research Faculty) - 303-724-5953 (office); 303-919-0793 (cell) or [Lorraine.Kubicek@cuanschutz.edu](mailto:Lorraine.Kubicek@cuanschutz.edu).

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## Recruitment Studies

### **The eXtraordinary Babies Study: Researching the Natural History of Health and Neurodevelopment in Infants and Young Children with Sex Chromosome Trisomy**

**Principal Investigator:** Nicole Tartaglia, MD, MS

**Co-Investigators:** Shanlee Davis, MD; Rebecca Wilson, PsyD; Jen Janusz, PsyD;  
Susan Howell, MS CGC; Talia Thompson, PhD

**Purpose:** This study is designed to research the natural history of neurodevelopment, health and early hormonal function in infants with XXY/Klinefelter syndrome, XYY, XXX and other sex chromosome variations in an effort to identify early predictors of developmental and health outcomes. The Investigators will also evaluate different developmental screening tools in infants with sex chromosome variations so the investigators can develop recommendations for pediatrician caring for infants and young children with XXY/Klinefelter syndrome, XYY, XXX, and other sex chromosome variations.

**Eligibility:**

1. Children must be between the ages of 6 weeks to 12 months old
2. Children must have a prenatally identified diagnosis of XXY, XYY, XXX, XXYY or other sex chromosome variation
3. Additional screening criteria to discuss with staff

COMIRB#: 17-0118

**Study dates:** September 2017 – August 2022

**Study website:** <https://clinicaltrials.gov/ct2/show/NCT03396562>

**Contact Information:**

## Hearing Assessment for Children with Developmental Disabilities

Principal Investigator: Angela Yarnell Bonino, Ph.D., CCC-A

**Purpose:** For children with developmental disabilities, audiologists often report that they have difficulty measuring behavioral hearing thresholds. The current lack of behavioral procedures that are effective for evaluating hearing in children with developmental disabilities is a significant public health problem, resulting in delayed diagnosis and difficulty fitting amplification in this population. The purpose of this project is to determine the feasibility and reliability of measuring behavioral hearing thresholds in children with developmental differences with an innovative, observer-based procedure.

### Eligibility:

1. 2 to 5 years of age
2. Diagnosed delay or disorder that impacts at least one area of development. Particular interest in recruiting children with either Down syndrome or autism spectrum disorder.
3. No known permanent hearing loss.
4. Negative history for placement of pressure equalization (PE) tubes or other ear surgery.
5. Not under treatment for otitis media within the prior month.
6. Additional screening criteria regarding child's development.

CU Boulder IRB #: 16-0639

**Funding Source:** American Speech-Language-Hearing Foundation and National Institute of Health - 2019-2023

### Contact Information:

Email: [childhear@colorado.edu](mailto:childhear@colorado.edu)

Phone: 303-735-6252

Website: <https://www.colorado.edu/lab/chapl/>

## CASCADE Study: Cannabidiol (CBD) Study in Children with Autism Spectrum Disorder

Principal Investigator: Nicole Tartaglia, MD

**Purpose:** This study is a placebo-controlled clinical trial of oral CBD in children and adolescents with autism spectrum disorder evaluating the effect of CBD on symptoms of irritability, aggression, anxiety and social behaviors. Each participant will be enrolled in the study for 27-29 weeks, with 8 research visits. All participants will receive CBD for at least 12 weeks during the study, and some participants will receive CBD for the entire study period.

### Eligibility:

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3. Patients who are taking other medication(s) for behavior should be on a stable regimen of no more than 2 medications for at least 4 weeks before study screening and must maintain that regimen throughout the study.
4. Patients with a history of seizure disorders must currently be receiving treatment with a stable regimen of one or two anti-epileptic drugs, or must be seizure-free for 1 year if not currently receiving AEDs.
5. If patients are receiving educational, behavioral, and/or dietary interventions or therapies, they must be stable for 2 months prior to screening. Changes with school breaks are expected and do not apply.
6. BMI of between 12-32 kg/m<sup>2</sup>

**COMIRB #:**19-2168

**Funding Source:** Colorado Department of Health and Environment (CDPHE), 2020-2023

**Interested parties should call or email:**

Nana Welnick

720-777-8608

[CBDiAutismStudy@childrenscolorado.org](mailto:CBDiAutismStudy@childrenscolorado.org)

with their contact information.

**Coming Soon!**

## **Improving Outcomes Using Augmentative and Alternative Communication for Children Who are Deaf or Hard of Hearing A Technology-Assisted Language Intervention Randomized Controlled Trial**

Principal Investigator: Jareen Meinzen-Derr, Ph.D. (Cincinnati); Local PI: Deborah Mood, Ph.D.

**Purpose:** This study is a multi-site study exploring different methods of language intervention that might help improve language skills of children who are deaf/hard of hearing. Specifically, this study looks at the effectiveness of using technology-assisted intervention (Augmentative and Alternative Communication- AAC) to improve language outcomes for children who are deaf/hard of hearing.

**Eligibility:**

1. Ages 3-10 years old
2. Permanent bilateral hearing loss
3. Able to participate in speech/language therapy delivered in English
4. Language delay OR gap between language functioning and nonverbal cognitive functioning (will be screened as part of eligibility consideration)

**Funding Source:** NIH/NIDCD, 2020-2025

**Contact Information:**

Deborah Mood, Ph.D.

Email: [Deborah.Mood@childrenscolorado.org](mailto:Deborah.Mood@childrenscolorado.org)

Phone: 720-777-2778

## Recent Publications

### Peer-Reviewed Journal Articles 2020 by JFK Faculty and Fellows

1. **Berkovits, L.D.**, Moody, C.T., Blacher, J. (2020). I don't feel different. But then again, I wouldn't know what it feels like to be normal. Perspectives of Adolescents with Autism Spectrum Disorder. *J Autism Dev Disord*, 50(3):831-843. DOI: [10.1007/s10803-019-04309-1](https://doi.org/10.1007/s10803-019-04309-1)
2. Berry-Kravis, E., Horrigan, J., **Tartaglia, N.**, Hagerman, R., Kolevzon, A., Erickson, C.A., Hatti, S., Snape, M., Yaroshinsky, A., Stoms, G. FXS-001 Investigators. (2020). A Double-Blind, Randomized, Placebo-Controlled Clinical Study of Trofinetide in the Treatment of Fragile X Syndrome, *Pediatric Neurology*, 110:30-41. <https://doi.org/10.1016/j.pediatrneurol.2020.04.019>
3. Burrell L.T., **Postorino V.**, Scahill L., Rea, H.M., Gillespie, S., Evans, A.N., Bearss, K. (2020). Feasibility of Group Parent Training for Children With Autism Spectrum Disorder and Disruptive Behavior: A Demonstration Pilot. *J Autism Dev Disord*. [published online ahead of print] <https://doi.org/10.1007/s10803-020-04427-1>
4. Carter, R.M., Jung, H., **Reaven, J.**, **Blakeley-Smith, A.**, & Dichter, G.S. (2020). A nexus model of restricted interests in Autism Spectrum Disorder, *Frontiers in Human Neuroscience*, 14, 212. <https://doi.org/10.3389/fnhum.2020.00212>
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6. Cola, M. L., Plate, S., **Yankowitz, L.**, Petrulla, V., Bateman, L., Zampella, C. J., ... & Parish-Morris, J. (2020). Sex differences in the first impressions made by girls and boys with autism. *Molecular Autism*, 11(1), 1-12. <https://doi.org/10.1186/s13229-020-00336-3>
7. **Cordeiro, L.**, **Braden, M.**, **Coan, E.**, **Welnick, N.**, **Tanda T.**, **Tartaglia, N.** (2020). Evaluating Social Interactions Using the Autism Screening Instrument for Education Planning-3rd Edition (ASIEP-3): Interaction Assessment in Children and Adults with Fragile X Syndrome, *Brain Sciences*.10(4):248. <https://doi.org/10.3390/brainsci10040248>
8. **Cordeiro, L.**, **Villagomez, A.**, Swain, D., Deklotz, S., **Tartaglia N.** (2020). Adaptive Functioning Skills in FXS: A Review of the Literature and Evaluation of the PEDI-Computer Adaptive Test to Measure Adaptive Skills, *Brain Sciences*, 10(6):e351. <https://doi.org/10.3390/brainsci10060351>
9. D'Agati, E., Abate, R., Gialloreti, L.E., Napolitano, C, **Postorino, V.**, Curatolo, P., Mazzone, L. (2020). Sleep Problems in attention-deficit/hyperactivity Disorder and Autism Spectrum Disorder: Sex Differences and Parental Stress. *Psychiatry Research*. [published online ahead of print] <https://doi.org/10.1016/j.psychres.2020.113099>
10. Danielson, M., Bitski, R.H., Holbrook, J.R., Charania, S.N., Claussen, A.H., McKeown, R.E. Cuffe, S.P., Sarno Owens, J., Evans, S.W., **Kubicek, L.F.**, & Flory, K. (2020). Community-based prevalence of externalizing and internalizing disorders among school-aged children and adolescents in four geographically dispersed school districts in the United States. *Child Psychiatry & Human Development*, 1-15. <https://doi.org/10.1007/s10578-020-01027-z>
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13. Hallgrímsson, B., Aponte, J., Katz, D., Bannister, J., Riccardi, S., Mahasuwan, N., McInnes, B., Ferrara, T., Lipman, D., Neves, A., Spitzmacher, J., Larson, J., Bellus, G., Pham, A., Aboujaoude, E., Benke, T., Chatfield, K., Davis, S., Elias, E., Enzenauer, R., French, B., Pickler,

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  16. **Kubicek, L.F.**, Thompson, L.J., Luna, A., Henderson, S., & Hubbard, R. (2020). Closing the gap through enhanced, family-centered approaches to care navigation: Increasing successful referrals for developmental delays with Colorado Project LAUNCH. *ZERO TO THREE*, 40(3), 48-56. <https://zerotothree.sharepoint.com/:b/g/productservices/EQOD8UxN7vJCjpXRb0Z5UVAB5UUJaTEoN486Iso74UyTUQ>
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26. **Thompson, T.**, Zieba, B., Howell, S., Karakash, W., Davis, S. (2020). A mixed-methods study of physical activity and quality of life in adolescents with Turner syndrome, *American Journal of Medical Genetics*, 182(2):386-396. <https://doi.org/10.1002/ajmg.a.61439>
27. **Thompson, T.**, Talapatra, T., Hazel, C., Coleman, J., & Cutforth, N. (2020). Thriving with Down syndrome: A qualitative multiple case study. *Journal of Applied Research in Intellectual Disabilities*. [published online ahead of print] <https://doi.org/10.1111/jar.12767>
28. **Thompson, T.**, **Howell, S.**, Davis, S., **Tartaglia, N.** (2020). Early Childhood Intervention Services in Sex Chromosome Aneuploidies. *Journal of Investigative Medicine*, 68(1), 255. <https://doi.org/10.1002/ajmg.c.31785>
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31. Wigby, K., **Cordeiro, L.**, **Wilson, R.**, Angkustsiri, K., Simon, T.J., **Tartaglia, N.** (2020). Adaptive Functioning in Children and Adolescents with Trisomy X: An Exploratory Analysis, *American Journal of Medical Genetics Part C – Seminars in Medical Genetics*, 184(2):456-468. <https://doi.org/10.1002/ajmg.c.31803>
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## Artists Corner



The following poem was written by **Edwin Austgen, age 12.**

In his free time Edwin enjoys working on models of ships and planes, drawing and reading about history, Edwin was diagnosed with autism spectrum disorder when he was 10 years



## Spoken words Poem

Mercury, Venus, Earth, Mars, Jupiter, Saturn, Uranus, Neptune and Pluto. Titanic, Planes, Boeing, Trains, Cars, and Buses. I love history, science, space and facts.

I was born August 14, 2008. That makes me a Leo. Leo's are creative and intelligent. My ruling planet is the sun, but I think the sun is a star. Leo's colors are red, gold and yellow because those are the colors of fire. Glowing, heat, flames, I am a Leo.

I am the shortest member of my family. I have to ask for the maple syrup at breakfast, because it's kept on a shelf too high for me to reach. That bugs me. People are all above me looking down, except for my dog. I'm taller than my dog.

Always be happy because everyday is going to be a good day, these are the words I live by. Because when it's not a good day, I think about when it was a good day. It's always my choice to be happy. The advice I would give is always ignore people who make fun of you for who you are. Never listen to them talk, you have to make your voice louder than theirs with self talk. The key to having a good life is being happy.

Anxiety is a part of my life. My heart races faster than a race car at Nascar. It feels like people are looking at me in a weird way. It feels like they always have. I ask myself why am I different, but I think there is nothing wrong with me. " Why fit in when you were born to stand out." When hearing music I see the notes in my head, I see the pieces of things instead of the whole thing. My brain is fast, I am quick at everything. Informant goes fast in my brain and I feel like I have to get it out before the next bunch of stuff goes into my brain. My mouth can never keep up. I think it's okay to stand out.

I like being alone. People are loud. The smells bother me. The sounds and smells of people are painful. I hate the breath of a whisper, their heavy shadow standing behind me. Baby cries, high pitch voices, I always want to scream stop. I used to do that. I don't anymore. People didn't like that they annoyed me.

The sound of a plane above my head is exciting. It's new places, new sites. I'm going to be there someday. That will be me flying. You take off at 180 miles per hour. A little turbulence wouldn't bother you. It's just a little wobbly. You would see the whole entire sky. You wouldn't feel anything in the sky at 700 miles per hour.

Pilots go from point A to point B, I want to go from Point A to Z.  
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