

Message from the Research Director



Judy Reaven, PhD
Director of Research
Associate Director, JFK Partners

Dear Community Partners,

We are excited to welcome you to the second edition of the Developmental Pediatrics/JFK Partners Research Newsletter! So much has happened in the past year, and we are eager to share with you some of our newest projects!

Spotlight!

In this issue, we have chosen to highlight the work of **Elizabeth Griffith, PhD**, Associate Professor of Pediatrics and clinical psychologist. She shares information about her research on early intervention for young children with Autism Spectrum Disorder.

"Advancing research in diverse communities will ...

*Sandra L. Friedman, MD, MPH
Section Head, Developmental Pediatrics
Director, JFK Partners*

Research Updates

In this section, you will read about current updates on a number of research projects that are either ongoing or have been recently completed within Developmental Pediatrics/JFK Partners. In keeping with the topic of this year's conference, Breaking Barriers: Cultural and Socioeconomic Considerations in Working with Diverse and Underserved ASD/IDD Communities we have included a section on **Advancing Research in Diverse Communities**.

Additions to our Research Team

We want to introduce you to two new members of our research team: **Richard Boles, PhD**, an Associate Professor at the University of Colorado Anschutz Medical Campus and clinical psychologist and **Valentina Postorino, PhD**, a clinical psychologist from the Marcus Autism Center and Emory University School of Medicine

Recent Publications

Many of those who have participated in our studies often ask about our research findings, so we have included a list of recent publications.

Study Recruitment

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

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. Share your thoughts with us here: <https://www.surveymonkey.com/r/2018jfknews>.

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Richard E. Boles, PhD

Associate Professor of Pediatrics
Associate Director of Research, DP/JFK Partners
University of Colorado Anschutz Medical Campus

Dr. Richard Boles joined the Section of Developmental Pediatrics / JFK Partners this summer as Associate Director of Research with Dr. Judy Reaven. Dr. Boles will work with faculty and learners at various levels to support ongoing studies and generate new research projects. Specifically, he will be involved in multiple facets of research, including project conceptualization, grant review, and analytic support. He will also lead and co-lead small group teaching at journal club and seminars.

Dr. Boles is a pediatric psychologist with specialization in child behavior and nutrition. He earned his doctoral degree in clinical child psychology from the University of Kansas and completed his residency and fellowship at Cincinnati Children's Hospital Medical Center. He currently provides individual and group outpatient services in the Lifestyle Medicine Weight Management Clinic and Adolescent Metabolic and Bariatric Surgery Center at Children's Hospital Colorado.

Dr. Boles is currently federally funded to conduct basic and patient-oriented research on pediatric obesity with specific interests in low-resource, minority populations and children with Intellectual and Developmental Disabilities (IDD).

His primary research foci examine social and physical environmental influences on weight development from infancy through adolescence. Current projects include measuring the impact of sleep functioning on child dietary intake and weight status and disseminating an obesity intervention program in primary care and community-based recreation centers for low-income, Latino families. Additionally, he has ongoing projects on instrument development and psychometric testing, evaluating adolescent patients with IDD seeking bariatric surgery, and direct observation based research of health behaviors in the home environment.



Valentina Postorino, PhD

Instructor
Research Manager, DP/JFK Partners
University of Colorado Anschutz Medical Campus

Dr. Valentina Postorino joined the Section of Developmental Pediatrics / JFK Partners in September as a Research Manager with Dr. Judy Reaven. In collaboration with Dr. Reaven and Dr. Boles, Associate Director of Research Manager, Dr. Postorino will support current and future research development among faculty, fellows, and students. Additionally, she will foster research partnerships across campus and provide support for grant development, provide statistical and methodological consultation, and conduct research focused teaching opportunities to faculty, fellows, and students at journal club, research seminars, and other campus venues.

Dr. Postorino is a pediatric psychologist with specialization in autism spectrum disorder. She earned her doctoral degree in clinical and developmental psychology from the University of Rome La Sapienza (Italy). She completed her residency at the Children's Hospital Bambino Gesù' of Rome (Italy). Dr. Postorino was a postdoctoral fellow at the Children's Hospital Bambino Gesù' (Italy) for approximately 2 years and six months. She was a postdoctoral fellow at Emory University, Marcus Autism Center, NIH Center of Excellence for Autism. She currently performs diagnostic evaluations at Brain and Body integration Mental Health Clinic, and she will support and conduct research at the University of Colorado, Department of Pediatrics/JFK.

She is a board certified therapist and trainer in the Research Unit for Behavior Intervention parent training program for children with autism and disruptive behaviors. Her primary research have focused on diagnosis and treatment outcomes for children and adolescents with developmental disabilities (e.g., autism spectrum disorder, attention deficit/hyperactivity disorder, genetic syndromes). Current projects utilize behavioral methodologies to elucidate active mechanisms in the pathogenesis and treatment of developmental disabilities.

Specifically, she is interested in evaluating the implementation of behavioral interventions in community clinical settings (e.g., the efficacy of the RUBI PT in clinical settings), in other clinical populations (e.g., down syndrome), and expanding the PT program to other clinical populations to target other clinical features (e.g., feeding difficulties and /or sleep problems).

Spotlight!

An interview with Elizabeth Griffith, PhD Associate Professor and Clinical Psychologist Section of Developmental Pediatrics

How did you become interested in research?

As an undergraduate I had the life-altering opportunity to work in a school for children with Autism Spectrum Disorders (ASD) and was 'hooked' on attempting to understand this complex disorder. I would dash to the school from my college two towns over in order to ensure more time working in this setting. At the same time, through my coursework and independent research, I was learning the power of experimental design to answer important questions about why we all do the things we do. I was excited to then integrate my developmental, cognitive, clinical, and research interests in graduate school at the University of Denver's Child Clinical Psychology program. There I had excellent mentorship and training from Dr. Bruce Pennington and Dr. Sally Rogers around conceptualizing and implementing strong research, as well as focusing on the questions that are important to outcomes for children with ASD and their families. It has been exciting to build on those skills, working to determine the factors that underlie the course of development in ASD, and those that lead to uptake of evidence based early autism interventions by families and community providers.

What is your area of research?

My primary study is on the impact of receiving an early diagnosis of autism and intervention on not just the child, but also their family. My current project, "Parent Mediated Interventions in Autism: The Search for Meaningful Outcomes," is designed to partner with families to redefine 'success' following intervention. While interventions for young children with ASD certainly are designed to develop the skills they need to improve their day-to-day functioning, it is also important to support the whole family. In the first phase of this project we explored themes in family narratives related to their experiences. We then used these themes to guide selection of measures for the ongoing second phase of the project. By Fall of 2018 we will have finished data collection on measures of child, parent, and family outcomes with families participating in our clinical service "Parent Coaching in the Strategies of Early Start Denver Model". Our goal is to shape the clinical services offered, as well as the measurement battery in studies of interventions.

In addition I am involved in research examining ways to expand the use of evidence based early autism interventions by service providers in low resource communities. This project compares two different intervention models and methods of dissemination. Data collection for this study is expected to run into Spring of 2019.

Describe practical implications of your research

Our research is designed to partner with families and illuminate ways for interventions to encourage family quality of life, parental health and cognitions, and parent-child interactions. Our interdisciplinary clinical and research teams believe that understanding meaningful and functional outcomes leads to improved interventions and therefore child and parent well-being. This is an example of how research and clinical service inform and strengthen one another.

"Our interdisciplinary clinical and research teams believe that understanding meaningful and functional outcomes leads to improved interventions and therefore child and parent well-being. This is an example of how research and clinical service inform and strengthen one another."



**Elizabeth Griffith, PhD
Associate Professor
Developmental Pediatrics
University of Colorado School of Medicine
Children's Hospital Colorado**

Research Updates

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

The eXtraordinary Babies Study evaluates the early health and development of infants and children with sex chromosome disorders. This study follows babies, who were diagnosed with a sex chromosome disorder before being born, from 2-3 months of age every 6-12 months as they grow up. This is an amazing opportunity to learn about the natural history of neurodevelopment, health and early hormonal function in infants with XXY/Klinefelter syndrome, XYY, XXX and other sex chromosome variations. We hope to identify early predictors of developmental and health outcomes observed in the variability in these conditions from a young age that will allow us to counsel families and develop specific treatment programs for these eXtraordinary kids. In the study, we will closely evaluate and track developmental skills, medical problems, hormone levels, body composition, and other important factors such as family history, interventions, and family quality of life. Funded by an NIH grant awarded to Dr. Tartaglia. See Study Recruitment Section about how to join this study.



Growing up with an extra X or Y: The TRIXY study

Principal Investigator: Nicole Tartaglia, MD, MS

Development can vary in children with an extra X or Y chromosome. It is therefore important to identify children with developmental differences so that appropriate interventions and supports can be provided as soon as possible. We have limited knowledge about development in these areas in young children with an extra X or Y chromosome, and there is still a lot for us to learn. In this study we are hoping to identify early markers to know which children are at higher risk for behavioral and social skills differences. With this knowledge, we hope to understand risk and protective factors so that we can provide better care for young children with a diagnosis of XXY, XXX or XYY. Study procedures include developmental assessment, play observations, eye tracking during video observation, and heart rate monitoring. Funded by a grant awarded to Sophie van Rijn, PhD at Leiden University. See Study Recruitment Section about how to join this study.

FX-LEARN: AFQ056 for Language Learning in Children with Fragile X Syndrome

Principal Investigator: Nicole Tartaglia, MD, MS

The purpose of this study is to find out if pairing an investigational drug with a structured language intervention leads to greater improvements in language skills compared to language intervention alone. The drug AFQ056, is an investigational drug that blocks the excess glutamate signaling that occurs in FXS. Participants are randomly assigned (flipping a coin) to receive either medication or placebo (fake medication) for 12 months. After 12 months, all participants will take AFQ056 for 8 months during the open-label extension portion of the trial. All children receive specialized language intervention which is designed to improve and stimulate language and communication in young children with FXS. This study is funded by the National Institute of Neurological Disorders and Stroke (NINDS) and Novartis.

Colorado Fragile X Fall Conference for Educators, Providers and Families

November 9-10, 2018 — 9:00 AM—4:00 PM (option to sign up for 1 day or both days)

University of Denver—Ruffatto Hall, Denver, CO 80208

<https://www.eventbrite.com/e/colorado-fragile-x-educator-conference-2018-tickets-50761150969>

Speakers: Dr. Karen Riley, Dr. Marcia Braden, Dr. Jeanine Coleman

For questions and info contact: denverfragilex@gmail.com or 720-841-5489

Facing Your Fears Adapted for Schools

Principal Investigator: Judy Reaven, PhD / Judy.Reaven@ucdenver.edu

In our Newsletter last year, we shared that had recently received federal funding from HRSA to implement the Facing Your Fears (FYF) program (group cognitive behavior therapy for managing anxiety in children and adolescents with ASD) in public schools in Colorado. We are specifically interested in working with low-resource schools (elementary and middle schools) and underrepresented racial/ethnic minority students with ASD or social/communication challenges similar to ASD. We have just completed the first year of a three-year HRSA grant to modify FYF in the Denver Metro area. We are partnering with the Cherry Creek School District, Denver Public Schools and Littleton Public Schools for this project. Special thanks to Connie Egleston (CCSD), Michelle Butler (LPS) and Sheri Katzman (DPS) for all their hard work in getting this project started!

The primary aims of this study are to: 1) Adapt the clinic-based Facing Your Fears program for school settings with input from key stakeholders (school professionals and parents); 2) Implement the school-based Facing Your Fears program (FYF-SB) in low-resource schools across three major school districts in Denver, using a “train the trainer” approach.

During this first year, we met with parents and professionals from all three districts and held a total of 14 focus groups. The purpose of the focus groups was to obtain feedback from the participants on how to modify FYF for public schools and for underrepresented racial/ethnic minority students. We are currently analyzing the data and are using the information from the participants to inform the development of the school based Facing Your Fears program. Eleven schools have been identified and interdisciplinary schools teams are beginning to deliver the intervention to students with ASD and anxiety this semester. We hope to expand the program to 10 schools per district next fall, and look forward to sharing more formal results of this project. Many thanks to our fantastic school partners at each district, as well as the many families who have participated in this project. Funding: HRSA R41MC31075.

JFK Partners/Developmental Pediatrics faculty and staff on this project: Audrey Blakeley-Smith, PhD, Nuri Reyes, PhD, Richard Boles, PhD, Lisa Hayutin, PhD, Caitlin Walsh, PhD, Allison Meyer, PhD, Katherine Pickard, PhD, and Tanea Tanda. Other staff: Susan Hepburn, PhD, (Colorado State University), Megan Morris, PhD (Adult and Child Consortium for Health Outcomes Research and Delivery Science (ACCORDS) University of Colorado Anschutz Medical Campus and Aubyn Stahmer, PhD, MIND Institute, University of California – Davis.

Facing Your Fears Adapted for Adolescents with ASD and ID

Principal Investigator: Audrey Blakeley-Smith, PhD
Audrey.Blakeleysmith@ucdenver.edu

Our research team has spent two years piloting a Facing Your Fears program for adolescents with Autism Spectrum Disorders, intellectual disabilities, and anxiety. The treatment program has been adapted to meet the needs of teens with limited language abilities and complex behavior. To date, 19 families have completed the program. Many thanks to these families as they have been instrumental in helping us determine what strategies are most effective in supporting teens to be brave and manage their anxiety. Our research group is currently working to finalize the treatment manual and further examine the program’s effectiveness. Funding: Organization of Autism Research (OAR).

For more information about Facing Your Fears, check out our website at:

<http://www.FacingFears.org>

Participating Schools

Cherry Creek School District



Our Vision:
Respecting our past, Valuing our present,
Believing in our future.

Denver Public Schools



A COMMUNITY GROWING TOGETHER



— ELEMENTARY —



Littleton Public Schools



POWELL

Pumas



Centennial Academy

of Fine Arts Education

Research Updates

GAIN Research Study

Principal Investigator: Susan Johnson, PhD Susan.Johnson@ucdenver.edu

Some foods are designed to support children's growth and development. The purpose of this research is to understand how children respond to one food. The GAIN study consists of two scheduled visits where you and your child will come to the Children's Eating Lab on CU Anschutz Medical Campus for an hour visit. During the first lab visit, you will offer a food to your child. We have two versions of this food, each of which is a mixture of a nut butter and infant oatmeal. Once your child has tasted the food, we will give you the opportunity to try it as well. Parts of the visit will be recorded so that we can monitor your child's reaction. After the feeding, we will take height and weight measurements for both you and your child. At the end of the first visit, we will send home 10 pre-weighed servings of oatmeal, 10 packets of the nut butter, and instructions for how to offer the food to your child over the next 2 weeks at home. We will schedule a second lab visit for you to return to The Children's Eating Lab. The second lab visit will be very similar to the first visit, with the addition of an interview at the end. The questions will focus on your experience of feeding the food to your child at home.

Evaluation of Inclusive Higher Education Pilot Program

Principal Investigator: Cordelia Robinson Rosenberg, PhD, RN
Cordelia.Rosenberg@ucdenver.edu

Dr. Rosenberg leads the program evaluation for the Colorado Inclusive Higher Education (IHE) Pilot program, which began its second of four years on July 1, 2017. This program is authorized through [Senate Bill 196](#). The three schools participating are Arapahoe Community College, University of Colorado at Colorado Springs, and University of Northern Colorado. JFK Partners is conducting the evaluation activities which involve documentation of program activities, policies and outcomes against nationally accepted program standards. Evaluation also includes interviews or surveys of key stakeholder groups including enrolled students, parents, faculty, peer mentors and typical students. More information can be found on the IN! website at www.inclusivehighered.org. Funding: State of Colorado, Senate Bill 196.

Crisis Plan Intervention

Principal Investigator: Cordelia Robinson Rosenberg, PhD, RN
Cordelia.Rosenberg@ucdenver.edu

For a number of years medical students in the LEADS program have focused on Crisis Intervention for people with a dual diagnosis of intellectual disability and mental illness or behavioral disability. The current project has involved developing a template for a crisis plan for these individuals and their families. As part of this research study, we work with families to complete a crisis plan using an approved template and crisis resource guide. This protocol is open to parents of a dually diagnosed individual of any age who lives with his or her parents. See the Study Participant table for more information on how to enroll.

DBPNet

Sandra L. Friedman, MD, MPH is the site lead for Colorado for the Developmental Behavioral Pediatrics Research Network (DBPNet). We are one of 14 sites of sites; other sites include Boston Children's; CHOP; Stanford; Cincinnati Children's; Einstein; Rainbow Babies; Yale; LA Children's; Boston Medical Center; Arkansas Children's; Hasboro Children's; UC Davis; Oklahoma.

Current active study: A Retrospective Description of the Effectiveness and Adverse Effects of Stimulants and Alpha-2 Agonists Used by Developmental-Behavioral Pediatricians for the Treatment of ADHD in Preschool Age Children. We have received IRB approval and the study is now beginning. This study involves 7 of the 14 DBPNet sites.

Soon to begin: The Role of ADOS in Diagnosis of Autism by Developmental Behavioral Pediatricians. This is a prospective study to determine the frequency with which results of the ADOS-2 alters the diagnostic conclusion of developmental-behavioral pediatricians. This study involves 5 of the 14 DBPNet sites.

Help us learn more about
child development.

SEED

Study to
Explore Early
Development

Study to Explore Early Development (SEED 3)

Principal Investigator: Cordelia Robinson Rosenberg, PhD, RN
Colorado.SEED@ucdenver.edu
303-724-7680

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 will help identify factors that might put children at risk for ASD and help improve services and treatments for children with ASD. SEED 3 is open to enrollment by invitation only. You can visit the Colorado SEED Study website at www.coloradoseed.org. Funding: CDC, National Center for Birth Defects and Developmental Disabilities, #5U01DD00120.

Study Recruitment

Project Name	Who is Eligible	Contact Information
<p>Efficacy of Crisis Plans for Individuals with Neurodevelopmental and Behavioral Dual Diagnosis</p> <p>COMIRB # 17-0845 PI: Cordelia Robinson Rosenberg, PhD, RN</p>	<p>We are enrolling parents of an individual who has both a neurodevelopmental diagnosis AND a psychiatric or behavioral diagnosis.</p> <ol style="list-style-type: none"> 1. Individual with dual diagnoses must be between 8-50 years of age 2. Individual must live in the state of Colorado 3. Individual with dual diagnoses must have experienced one or more of the following events: <ol style="list-style-type: none"> (a) 911 call; (b) Emergency Department admission for mental health reasons; or (c) other urgent mental health intervention. 4. Parent or caregiver must be willing/able to complete the Crisis Plan and follow up surveys. 	<p>Cordelia Robinson Rosenberg, PhD, RN 303-724-7366 Cordelia.Rosenberg@ucdenver.edu</p>
<p>The GAIN Study</p> <p>COMIRB # 17-2308 PI: Susan L. Johnson, PhD</p>	<p>To participate your child must:</p> <ol style="list-style-type: none"> 1. Be between 7-24 months 2. Have been born to term, 3. NOT have any allergies or medical conditions. <p>To participate you must:</p> <ol style="list-style-type: none"> 4. Be between 18 and 50 years old 5. NOT have any nut allergies. 	<p>Abigail Flesher Abigail.Flesher@ucdenver.edu 303-724-2922</p>
<p>The eXtraordinary Babies Study: Researching the Natural History of Health and Neurodevelopment in Infants and Young Children with Sex Chromosome Trisomy</p> <p>COMIRB#17-0118 PI: Nicole Tartaglia, MD, MS</p>	<ol style="list-style-type: none"> 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 	<p>720-808-0873 extraordinarykids@ucdenver.edu</p>
<p>Growing up with an extra X or Y: The TRIXY study</p> <p>COMIRB#16-1710 PI: Nicole Tartaglia, MD, MS</p>	<ol style="list-style-type: none"> 1. Children must be between the ages of 1 years and 5 years old at enrollment 2. Confirmed diagnosis of 47,XXY, 47,XYY or 47,XXX or typically developing children 3. Additional screening criteria 	<p>Lisa Cordeiro, MS, CSP 720-722-1515 trixy@ucdenver.edu</p>
<p>FX-LEARN: AFQ056 for Language Learning in Children with FXS</p> <p>COMIRB# 17-1129 PI: Nicole Tartaglia, MD, MS</p>	<ul style="list-style-type: none"> • Males or females with a confirmed diagnosis of FXS • Individuals ages 32 months to 6 years 11 months on enrollment • Speak English as primary language- <p><i>There are additional inclusion criteria to be a part of this study. Please contact study staff for additional information.</i></p>	<p>Nana Welnick 720-777-8608 Nanastasia.Welnick@childrenscolorado.org</p>
<p>Study to Explore Early Development (SEED): Phase 3</p> <p>COMIRB # 16-1985 PI: Cordelia Robinson Rosenberg, PhD, RN</p>	<p>By invitation only, we are enrolling children:</p> <ol style="list-style-type: none"> 1. Were born in and currently live in one of the eight SEED study counties. 2. Are between the ages of 2-5. <p>Many different children are eligible to take part in SEED including:</p> <ol style="list-style-type: none"> 3. Children with ASDs 4. Children with other developmental disabilities 5. Children without developmental disabilities 	<p>Kristina Hightshoe, MSPH 303-724-7672 Kristina.Hightshoe@ucdenver.edu</p>

Advancing Autism Research in Diverse Populations

Reyes, N., Pickard, K., Reaven, J., and Reynolds, A.

<p>Stigma in ASD -Families of children with autism spectrum disorder (ASD) often experience stigma. In this study, an English/ Spanish bilingual parent-reported scale of perceived community ASD stigma was created and tested it in a multi-site sample of Latino and non-Latino white parents of children with ASD.</p> <p>-Findings from this study revealed that stigma score from the questionnaire was associated with unmet ASD care needs but not therapy hours or therapy types. Moreover, child public insurance, parent nativity, number of children with ASD in the household, parent-reported ASD severity, and family structure, were associated with higher stigma score.</p> <p>-Overall, this scale may be useful in assessing levels of stigma in parents of children with ASD and finding ways to reduce stigma in this population.</p>	<p>Parents' Beliefs about ASD -Parents of children with ASD hold certain beliefs about Autism Spectrum Disorder (ASD). Parents of children with ASD are recommended to seek services right after they receive their child's diagnosis. This study examined (1) beliefs about ASD among English language proficient White (EP-W) mothers, English language proficient Latino (EPL) mothers, and limited English language proficient Latino (LEP-L) mothers of children with ASD; (2) beliefs about ASD in the context of the child's ASD severity, among EP White mothers, EP Latino mothers, and LEP Latino mothers; and (3) the connection between maternal beliefs about ASD and children's current ASD services.</p> <p>-305 English, Spanish, or bilingual-speaking family with children with ASD, ages 2–10 years, completed a survey about their beliefs about their child's ASD, their child's ASD severity, and services received by their children.</p> <p>-Findings showed that beliefs about viewing ASD as a mystery were different in mothers in the EP-W, EP-L, and LEP-L groups. That is, mothers of children in the LEP-group were more likely to view ASD as a mystery. Also, beliefs about ASD were associated with maternal views of ASD severity in the EP-W group only. Finally, maternal beliefs about ASD having major consequences on their child's life, and ASD being a mystery were associated with a child's use of ASD services.</p> <p>-These results indicate that mothers from different backgrounds might hold different beliefs about ASD. These beliefs, in turn, may be associated with ASD services and ASD symptom severity for some families.</p>	<p>Barriers to Obtaining an ASD Diagnosis -Age of diagnosis tend to vary in children with ASD. This study examined barriers that may interfere with families' ability to obtain an early diagnosis. Also, the link between those barriers and current ASD-related service was examined in non-Latino white (NLW) families, and Latino families with English proficiency (L-EP) or limited English proficiency (L-LEP).</p> <p>-Results showed that families tend to experience a mean of 8 of 15 barriers to ASD diagnosis. The most frequent barriers overall were (1) "stress of diagnostic process," (2) "parent knowledge about ASD," and (3) "understanding medical system." Additionally, L-LEP families were more likely to report barriers associated with knowledge about ASD and trust in providers than NLW families. L-LEP families reported having fewer current therapy hours and more unmet therapy needs than children in NLW families. L-EP and NLM families had a similar barriers and treatment services use profile.</p> <p>-In general, this study demonstrates that families with children with ASD experienced barriers when trying to get an ASD diagnosis. Families without English proficiency were more likely to have increased barriers and fewer services. Disparity in diagnosis and service use may be addressed by increasing ASD-related knowledge and</p>	<p>CBT Research in ASD -Research shows that cognitive behavioral therapy (CBT) improves anxiety for youth with autism spectrum disorder (ASD). However, we don't know whether it has included youth and families from diverse and underrepresented and backgrounds.</p> <p>-Our goals were to answer these questions: 1) What is the race, ethnicity, and education background of youth with ASD and their families who have participated in research on CBT for anxiety?; and 2) How does the background of participating youth and families compare to the United States census?</p> <p>-We reviewed 14 studies that included 473 youth. Our results show that there are significantly more White youth and a significantly fewer Black and Latino youth in CBT research. There are also fewer caregivers with less than a college degree participating in CBT research when compared to the United States population.</p> <p>-Our results suggest that it is important to actively include families from diverse backgrounds in CBT research for anxiety in order to make interventions that are both high-quality and can meet the needs of diverse youth and families.</p>
<p>Zuckerman, K., Lindly, O., Reyes, N., Chavez, A., Macias, K., Smith, K., Reynolds, A. (2018). Parent perceptions of Autism Spectrum Disorder Stigma: Measure validation and associations in a multi-site sample. <i>Journal of Autism and Developmental Disorders</i>. https://doi.org/10.1007/s10803-018-3586-x</p>	<p>Reyes, N., Lindly, O., Chavez, A., Macias, K., Folan, A., Smith, K., Reynolds, A., & Zuckerman, K. A. (2018). Maternal beliefs about Autism: A link between intervention services and Autism severity in White and Latino mothers. <i>Research in Autism Spectrum Disorders</i>, 51, 38-48. https://doi.org/10.1016/j.rasd.2018.04.001</p>	<p>Zuckerman, K., Lindly, O., Reyes, N., Chavez, A., Macias, K., Smith, K., Reynolds, A. (2017). Disparities in diagnosis and treatment of Autism in Latino and Non-Latino white families. <i>Pediatrics</i>, 139, (5), p. 1-10. https://doi.org/10.1542/peds.2016-3010</p>	<p>Pickard, K., Reyes, N.M., Reaven, J. (2018). Short Report: Examining the Inclusion of Diverse Participants in CBT Research for Youth with ASD and Anxiety. <i>Autism: International Journal of Research and Practice</i>.</p>

Recent Publications

For copies of the listed publications, please contact the Principal Investigator listed below.

Facing Your Fears (FYF) Program: Group Treatment for Children & Adolescents with Autism Spectrum Disorder and Anxiety

Principal Investigator: Judy Reaven, PhD | Judy.Reaven@ucdenver.edu

Vasa, R., Keefer, A., Reaven, J., South, M., & White, S. (2017). Priorities for advancing research on youth with autism spectrum disorder and co-occurring anxiety. *Journal of Autism and Developmental Disorders*, 48(3), 925-934. <https://doi.org/10.1007/s10803-017-3320-0>

Keefer, A., Kreiser, N., Blakeley-Smith, A., Reaven, J., Singh, V. & Vasa, R. (2018). Exploring relationships between negative cognitions and anxiety symptoms in youth with autism spectrum disorder. *Behavior Therapy*, 49 (5), 730-740. <https://doi.org/10.1016/j.beth.2017.12.002>

Reaven, J., Moody, E., Klinger, L., Keefer, A., Duncan, A., O'Kelley, S., Meyer, A., Hepburn, S., & Blakeley-Smith, A. (2018). Training Clinicians to Deliver Group CBT to Manage Anxiety in Youth with ASD: Results of a Multi-Site Trial. *Journal of Consulting and Clinical Psychology*, 86(3), 205-217. <https://doi.org/10.1037/ccp0000285>

Walsh, C., Moody, E., Blakeley-Smith, A., Duncan, A., Hepburn, S., Keefer, A., Klinger, L., Meyer, A., O'Kelley, S., & Reaven, J. (2018). The relationship between treatment acceptability and youth outcome in group CBT for youth with ASD and anxiety. *Journal of Contemporary Psychotherapy*, 48(3), 123-132. <https://doi.org/10.1007/s10879-018-9380-4>

Keefer, A., Vasa, R., White, S., & Reaven, J. (2018). Psychosocial Interventions for Internalizing Disorders in Youth and Adults with ASD. *International Review of Psychiatry*, 30, 62-77. <https://doi.org/10.1080/09540261.2018.1432575>

Complementary Medicine

Lindly, O., Thorburn, S., Heisler, K., Reyes, N.M., Zuckerman, K., (2018). Parents' use of complementary health approaches for young children with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 48(5):1803-1818. <https://doi.org/10.1007/s10803-017-3432-6>

Parents use of complementary medicine was examined in 352 families of children with ASD from Denver, Los Angeles, and Portland. Results indicate 44.9% of families used one or more type of complementary medicine. Parents reported using vitamins (33.2%), herbal supplements (13.4%), special diets (13.1%), other approaches (7.7%), chiropractic, acupuncture, or massages (1.7%), and traditional healers (1.1%). Parents who believe ASD had major consequences in child's life, parents of younger children, parents living in Portland or Denver, and those with children using medication were more likely to report use of complementary medicine.

Lindly, O., Thorburn, S., Heisler, K., Reyes, N.M., Zuckerman, K., (2017). Parent disclosure of complementary health approaches used for children with autism spectrum disorder: Barriers and facilitators. *Complementary Therapies in Medicine*, 35:47-52. <https://doi.org/10.1016/j.ctim.2017.09.003>

Use of complementary medicine was examined in 31 parents of children with ASD. Parents were interviewed about their complementary medicine use. From these interviews, the following factors appear to influence parental disclosure of their use to their health providers: parents' drive to optimize their child's health, parent self-efficacy discussing complementary medicine with healthcare providers, parent beliefs about the effectiveness of complementary medicine, parent-provider relationship quality, provider attitudes and knowledge regarding complementary medicine and ASD, and visit characteristics.

Study to Explore Early Development

Principal Investigator: Cordelia Robinson Rosenberg, PhD, RN / Cordelia.Rosenberg@ucdenver.edu

Wiggins, L. D., Rubenstein, E., Daniels, J., DiGuseppi, C., Yeargin-Allsopp, M., Schieve, L. A., Tian, L., Sabourin, K., Moody, E., Pinto-Mattin, J., & Reyes, N.M. & Levy, S. (2018). A Phenotype of Childhood Autism Is Associated with Preexisting Maternal Anxiety and Depression. *Journal of Abnormal Child Psychology*, 1-10. [Epub ahead of print] <https://doi.org/10.1007/s10802-018-0469-8> .

This study investigated the characteristics of children of ASD and their mothers with a history of anxiety or depression in 672 dyads. Children were grouped as having: (type 1) mild language with cognitive rigidity, (type 2) significant developmental delay with receptive motor behaviors, (type 3) general developmental, (type 4) mild language and motor delay with dysregulation. Findings from this study revealed that 22.6% of mothers reported a diagnosis of anxiety or depression before the birth of their child. Also, maternal depression or anxiety was associated with type 4 (dysregulated ASD in child).

Recent Publications

For copies of the listed publications, please contact the Principal Investigator listed below.

Study to Explore Early Development

Principal Investigator: Cordelia Robinson Rosenberg, PhD, RN / Cordelia.Rosenberg@ucdenver.edu

Rosenberg, S.A., Moody, E.J., Lee, C, DiGuseppi, C, Windham, G.C., Wiggins, L.D., Schieve, L.A., Ledbetter, C.M., Levy, S.E., Blaskey, L., Young, L., Bernal, P., Rosenberg, C.R., and Fallin, M.D. Influence of Family Demographic Factors on Social Communication Questionnaire Scores. (2018). *Autism Research*, 11: 695–706. <https://www.DOI.org/10.1002/aur.1935>

Screeners are used to help identify children who are more likely to have ASD than their peers. Ideally screeners should be accurate for different groups of children and families. This study examined how well the Social Communication Questionnaire (SCQ) predicts ASD. We found that male sex, lower household income, lower maternal education and Black race were associated with higher SCQ scores. In this study an SCQ cut-point of 11 worked best across the different sociodemographic groups in our sample.

DiGuseppi C, Levy SE, Sabourin KR, Soke GN, Rosenberg S, Lee LC, Moody E, Schieve LA. (2018). Injuries in Children with Autism Spectrum Disorder: Study to Explore Early Development (SEED). *J Autism Dev Disord*, 48(2): 461-472. <https://www.doi.org/10.1007/s10803-017-3337-4>

This study evaluated injuries in preschool-aged children with and without ASD and other developmental disabilities (DDs). Parents of children were asked whether their child had ever had an injury that required medical attention, and what types of injuries had occurred. The study findings showed that injuries were common in all groups of children and there was little difference between groups. Parents reported injuries for 32% of children with ASD, 28% of children with other DDs, and 30% of children in the general population. The most common injuries were open wounds and fractures and the most common reason for injuries was falls. While there was a slight difference in injuries between children with ASD and other DDs, further study found that this was largely explained by a higher level of attention problems in the children with ASD.

Soke GN, Rosenberg SA, Rosenberg CR, Vasa RA, Lee LC, DiGuseppi C. (2018). Self-injurious Behaviors in Children with Autism Spectrum Disorder Enrolled in the Study to Explore Early Development. *Autism*, 22(5): 625-635. <https://www.doi.org/10.1177/1362361316689330>.

This study assessed self-injurious behavior, or SIB, among children with ASD. SIB includes head-banging, hair-pulling, arm-biting, scratching, and hitting oneself. SIB is usually mild, but can be severe in some children and may result in injuries requiring medical care. Children with severe SIB may miss out on educational and social activities. This study showed that in the SEED sample, about 28% of preschool-aged children with ASD displayed SIB currently, and 47% had previously displayed SIB. Researchers found SIB was more common in children with low adaptive behavior scores and gastrointestinal, sleep, and behavioral problems. While its causes are not completely understood, identifying SIB early is helpful because it may reduce the likelihood of more severe SIB later.

Rubenstein E, Wiggins LD, Schieve LA, Bradley C, DiGuseppi C, Moody E, Pandey J, Pretzel RE, Howard AG, Olshan AF, Pence BW, Daniels, J. (2018). Associations between Parental Broader Autism Phenotype and Child Autism Spectrum Disorder Phenotype in the Study to Explore Early Development, *J Autism*, 1-3. <https://doi.org/10.1177/1362361317753563>.

This study assessed how the variation in developmental features among children with ASD was related to their parents' own autism-related traits. The presence of autism traits in family members of children with ASD is commonly referred to as the "broader autism phenotype" or BAP. The study findings show that if one or both parents have traits consistent with BAP, the child's ASD is more likely to fall within a certain clinical presentation than if neither parent has traits consistent with BAP. This clinical presentation in the child is characterized by average nonverbal abilities, mild language and motor delays, and increased frequency of other co-occurring developmental difficulties such as anxiety, depression, aggression, and attention difficulties. The findings reported in this study could help better our understanding of the genetics of ASD.

Recent Publications

For copies of the listed publications, please contact the Principal Investigator listed below.

Early Childhood Mental Health

Kubicek, L.F., & Snowden, R.E. (2018, October). Partners in Parenting Education (PIPE): *Nurturing parent-child relationships through bilingual English-Spanish instruction*. ZERO TO THREE Annual Conference 2018, Denver, Colorado.

The Partners in Parenting Education (PIPE) curriculum provides parents of children ages 0 to 2 years with training to develop sensitive, responsive, and dependable caregiver-child relationships that can support and encourage optimal development. This poster will present self-report data from parents who are participating in bilingual English and Spanish PIPE classes.

Perkins, J., Kubicek, L.F., Knox, S., Rosendo, J., & Johnson, T. (2018, September). Parents and childcare providers partnering to support the social and emotional health and development of young children: Implementing relationship-based curricula at home and in Early Head Start settings. Engaging Communities in Education and Research, Breckenridge, Colorado.

Young children's social emotional health, which develops in the context of nurturing relationships, provides the foundation for overall health and well-being and is inextricably linked to success in school and life. This poster focuses on our successes and challenges to design a program that: (1) blends two curricula focused on the development of sensitive, responsive, and dependable caregiving relationships, and (2) fosters collaboration between parents and childcare providers while promoting parents as their child's first teacher.

Brophy-Herb, H.E., Dickstein, S., Kubicek, L.F., & Tomlin, A. (2018, May). *Building a framework for infancy/early childhood mental health workforce development through advocacy and training: The Alliance for the Advancement of Infant Mental Health*. World Association for Infant Mental Health, Rome, Italy.

High quality care that supports infant/early childhood mental health (IECMH) requires a well-trained workforce spanning disciplines and systems. Programs, agencies, and state governments need sustainable and strategic methods to build IECMH systems. The Alliance for the Advancement of Infant Mental Health is comprised of 31 US states and two other countries that support the IMH Competencies and Endorsement. Each year, the leadership of each Alliance organization completes a seven item survey regarding their activities during the calendar year, e.g., community collaboration, training, policy/systems development, and funding. This poster reports on the results of qualitative analysis of the responses to the 2016 survey.

Kubicek, L.F. (2017, December). *Family leadership and engagement guiding systems change in Early Childhood Mental Health*. ZERO TO THREE Annual Conference 2017, San Diego, California.

Family leadership and engagement in early childhood mental health systems change is an essential and valued component of Project LAUNCH, a federal initiative funded by SAMHSA. Benefits of family leadership and engagement to families and communities as well as challenges and solutions to maintaining authentic family engagement will be discussed.

Bitsko, R.H., Danielson, M., Holbrook, J.R., Flory, K., Kubicek, L.F., & Cuffe, S. (2017, October). *Development and implementation of an assessment tool for tic disorders including Tourette Syndrome (TS)*. Annual Meeting of the American Academy of Child and Adolescent Psychiatry, Washington, D.C.

This poster reports on efforts to estimate the prevalence of selected mental disorders among school-aged children and adolescents using a population-based two-stage study design in Colorado and South Carolina as part of the Project to Learn About Youth-Mental Health (PLAY-MH).

Reyes, N., Moody, E., Hightshoe, K., Davidon, S., Rosenberg, S., & Kubicek, L. F. (under review) *Performance of the Social Communication Questionnaire: An Examination of the English and Spanish Versions in a Non-ASD Sample*

The goal of this study was to examine factors that could influence scores on the English and Spanish versions of the Social Communication Questionnaire (SCQ) and therefore, the interpretation of those scores as well. Children and adolescents were included to examine the performance of the English and Spanish versions of the SCQ and to investigate the relation between SCQ-current scores and child and parent characteristics. A total of 199 English and Spanish speaking caregivers completed the SCQ. Results indicated that Spanish SCQ scores tend to be higher than English SCQ scores. Moreover, behavior problems and Spanish language tend to predict higher SCQ total scores. These findings suggest that when using the SCQ, researchers and clinicians need to be mindful that a high score on the SCQ does not necessarily indicate autism symptoms or characteristics. Rather, high SCQ scores might represent non-ASD problems, such as child and family characteristics or the quality of the Spanish translation.

Recent Publications

For copies of the listed publications, please contact the Principal Investigator listed below.

Early Intervention

Rosenberg, SA, Elbaum B, Rosenberg CR, Kellar-Guenther Y, McManus BM (2018). From flawed design to misleading information: The U.S. Department of Education's early intervention child outcomes evaluation. *American Journal of Evaluation*. 39, 350-363. <https://doi.org/10.1177/1098214017732410>.

It is a matter of concern when large, federally funded programs are evaluated using designs that produce misleading information. In this article, we discuss problems associated with an evaluation design that was adopted by the U.S. Department of Education, Office of Special Education Programs (OSEP) to document the performance of a major early intervention (EI) program, serving young children with developmental delays and disabilities. In particular, we focus on OSEP's requirement that states use a single group pre-post comparison design to evaluate the impact of EI on child outcomes. We also provide a data-based illustration that shows this evaluation design cannot distinguish child progress that is due to EI services from changes associated with other factors, such as regression to the mean. We hope this work will support the adoption of evaluation designs that are more in line with accepted principles of program evaluation.

Other various research posters and publications

Dempsey, J., Dempsey, A.G., Simons, A., Baalman, K.B. & Monteiro, S. (2018). Adaptive behavior profiles of intellectually gifted children with Autism Spectrum Disorder. *Society for Developmental and Behavioral Pediatrics*, Anaheim, CA.

This poster describes a research project designed to test whether the well-established pattern in children with ASD of declines in adaptive functioning (i.e., ability to handle common demands in life and be independent) as they age also manifests in intellectually gifted children with ASD. The increasing social demands of all aspects of life as children age is thought to cause this decline. IQ is strongly tied to adaptive functioning in most people, and we expected that gifted children could leverage their intellectual gifts to overcome this pattern. Examining the adaptive functioning of 51 intellectually gifted children with ASD, we found that they actually demonstrated more rapid declines in adaptive functioning as they aged compared to 2 age- and sex-matched groups of children with ASD with IQs falling in the average and Intellectual Disability ranges. Furthermore, the adaptive functioning of the gifted group was virtually indistinguishable from that of the average group. These findings indicate the social deficits of ASD impose a ceiling or cap beyond which additional gains in IQ do not produce gains in adaptive functioning. The dataset used in this publication came from the Simons Simplex Collection.

Hedgecock JB, Dannemiller LA, Shui AM, Rapport MJ, Katz T. (2018). Associations of Gross Motor Delay, Behavior, and Quality of Life in Young Children With Autism Spectrum Disorder. *Physical Therapy*. 9;98(4):251-9. <https://doi.org/10.1093/ptj/pzy006>.

This article describes the association between problem daytime behaviors, quality of life, and gross motor delays in children with ASD. These findings were based on an analysis of data collected by the Autism Speaks Autism Treatment Network and included over 3,000 children who were between 2 and 6 years of age with ASD. Problem day time behaviors occur during waking hours and can include both internalizing (e.g., emotional reactivity, depression, withdrawal) and externalizing (e.g., hyperactivity, aggression, attention deficits) behaviors. The authors concluded that early evaluation by a physical therapist could be beneficial in addressing gross motor delays in these children.

Moody, E.J., Kaiser, K., Sharp, D., Kubicek, L.F., Ricles, B., Davis, J., McSwegin, S., D'Abreu, L.C., & Robinson Rosenberg, C. (under review). Improving family functioning following diagnosis of ASD: A randomized trial of a parent mentorship program.

Autism spectrum disorder (ASD) impacts family functioning and quality of life. This study investigates a comprehensive support program for families of children newly diagnosed with ASD. The Colorado Parent Mentoring (CPM) program combines family centered action planning and education with ongoing parent-to-parent mentorship. In a randomized controlled trial, the intervention was given to a group of parents and compared to a waitlist group. The intervention improved satisfaction with disability related services and prevented rigidity in how the family functions. Services used outside of school increased for all participants but did not meet the national recommendation. The CPM program may be a useful tool for helping families cope with their child's ASD; although, additional research is needed to confirm these effects.

Upcoming Opportunities

Please be on the lookout for our next Research Newsletter in October 2019. We aim to provide updates on current research and will highlight new ways to get involved. Please share your ideas for future newsletters with us here: <https://www.surveymonkey.com/.r/2018jfknews> .

JFK Listserv

If you would like to hear about all of the ongoing opportunities at JFK Partners, please join our listserv by sending an email to: Listserv@Lists.UCDenver.edu with "Listserv Command" in the Subject Line and "SUBSCRIBE JFKPARTNERS" in the text of your email. If you have trouble, please email Dina.Johnson@ucdenver.edu.

We invite you to follow us on Facebook @JFKPartners



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