

Message from the Research Director

Dear Community Partners,

Welcome to our Spring Research Newsletter 2020! Like many of you, we have experienced significant disruptions due to COVID-19. Many of our research projects have been unable to actively recruit new participants, and for other studies, we have been unable to continue to provide in-person treatments. Although there are many challenges that have arisen over the past month, we have found new and innovative ways to continue to conduct high quality research while adhering to social distancing, and hope to share some of these innovations with you in subsequent newsletters. This newsletter was prepared before COVID-19 quarantines occurred. Resources for families during COVID-19 have been curated by the Dev Peds/JFK team here: <https://tinyurl.com/DP-JFK-COVID19>

Spotlight!

In this issue, we are highlighting the work of Elizabeth Coan, PsyD, Clinical Psychologist with Developmental Pediatrics. Over the past year, she has worked with the Pediatric Care Network (PCN) at Children's Hospital Colorado, forging partnerships with pediatric practices across the Metro area. Learn more about her efforts on p.2.

Research Updates

Check out the research updates section for information on projects that are currently ongoing or have been recently completed. In addition, DevPeds/JFK Partners is committed to interdisciplinary training and as part of the Leadership and Education in Neurodevelopmental and Related Disabilities (LEND) fellowship, all of our fellows are required to complete a scholarly project. In this issue, we have included a table of all of our current LEND fellows' proposed projects to give you an idea about the range of interests and topics that our fellows are studying. Finally, there is also exciting news about several new research projects so be sure to take a look!

Recent Publications

Recent publications are listed at the end of the newsletter.

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. Please share your thoughts with us here: <https://www.surveymonkey.com/r/2020SpringNews>.

Warmly,




Judy Reaven, PhD
Professor of Psychiatry and Peds
Director of Research
Associate Director, JFK Partners



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

I am proud of our continuing work in the area of research during this challenging time. This newsletter highlights the importance of outreach and collaboration with community partners to improve quality and systems of care, as well as health outcomes, through innovative practice.

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

Save the Date!

JFK Partners 8th Annual
Autism Spectrum Disorder
Conference

*Shining a Light on Mental Health
in ASD
Across the Lifespan*

Friday, Oct 9, 2020
8:00 AM - 4:30 PM

Anschutz Medical Campus
Registration begins July 2020
www.JFKPartners.org

*The conference will take place using state and university COVID-19 policies and guidelines for Oct events.

COVID 19 Resources Overview

<https://tinyurl.com/DP-JFK-COVID19>

COVID-19 Resources for Individuals with ID/DD and ASD and their families	- COVID-19 Picture Communication Board (English)
	- Coronavirus Resources from Family Voices
	- Coping and emotion regulation strategies
	- Ensuring People Have Access to Prescription Drugs During the COVID-19 Pandemic
	- Guide to helping families cope with coronavirus
	- Mental Health and I/DD COVID-19 Resources from START
	- Parent/Caregiver Guide to Helping Families Cope with COVID-19
	- Plain-Language Information on Coronavirus (English and Spanish)
	- Social story about germs
	- Social stories in other languages
	- Social story about coronavirus
	- Strategies and tips to decrease fears and anxiety
	- Strategies to decrease stress and worry
	-Strategies to support individuals with ASD
	- Supporting Individuals with Autism through Uncertain Times
	- Supporting families with children with ASD
	- Visual Supports and social stories
	- COVID-19 Toolkit
Online Educational Supports for Parents	- COVID-19 Information and Resources for Schools and School Personnel
	- Online Learning Resources
	- OSEP COVID-19 – Serving Children with Disabilities- Announcement 3/21/20
	- Other learning resources
	- School Closure Toolkits
	- Teaching tools
Online Autism Resources for Parents	- Webinar for families with young children (<u>every week</u>)
	- Early Start Denver Model
	-Challenging Behaviors
	-ABA 101

Spotlight!

Elizabeth Coan, PsyD

Clinical Psychologist

Section of Developmental Pediatrics

The Pediatric Care Network & Developmental Pediatrics' Autism Pathway

This project aims to assess the development of a collaborative care and educational consultation model that bridges the gap between primary care and hospital-based evaluation and treatment services for children with ASD.

Individual practices participate in on-site training sessions related to ASD presented by Developmental Pediatrics. Once trained, these primary care providers begin the developmental evaluation in their office by conducting an autism-focused developmental history.

Patients are then referred to Developmental Pediatrics to complete the evaluation. This model saves in-clinic specialist's time during the evaluation, and conserves specialty resources following diagnosis, as the majority of families continue receiving care from their primary provider.

Since its inception in May of 2019, 13 primary care offices have completed the training, and over 100 primary care providers have participated. Families referred from these practices have waited an average of 2 months for their evaluation, which is a significant reduction in wait time compared to those on our general waitlists.

Primary care providers have expressed significant appreciation for this program, and have offered high praise for the educational sessions provided by Developmental Pediatrics.

Additional branches of the program, such as referrals for consultation with our resource team and genetic counselor have been built as a result of provider feedback.

It is hoped that all 33 practices within the PCN will complete the autism program training by the end of 2020.

Dr. Coan, along with other colleagues in Developmental Pediatrics presented this information for the JFK-MCH Education Series on April 1, 2020. The archived recording can be seen here: <https://tinyurl.com/ASDpathway>



Elizabeth Coan, PsyD
Clinical Psychologist

Dr. Coan's areas of special interest include assessment of developmental disabilities and co-existing mental health concerns, intervention for children with developmental differences and their families, program development, teaching and community outreach. Dr. Coan is heavily involved in the Psychology training program at Children's Hospital, and is the founder of the Autism Initiative Program within the Pediatric Care Network, which is an education and training program for Primary Care Providers working in community practices. She has prior experience as an Applied Behavior Analysis (ABA) therapist and has worked with children with developmental differences for approximately 15 years.



Goals of Study:

1. To train cross-disciplinary teams of school providers to deliver school-based Facing Your Fears in public schools.
2. To team with school providers to train other teams of school providers in their districts to deliver FYF-SB using a Train-the-Trainer approach.

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,
check out our website at:

<http://www.FacingFears.org>

Facing Your Fears in Schools: An Implementation Study to Manage Anxiety in Underserved Students with ASD or other Social/Communication Challenges (COMIRB Protocol: #17-0114 PI: Judy Reaven)

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 minute/week curriculum delivered by cross-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.

What have we done so far?

Phase 1: 2018-19

- JFK research team trained 34 interdisciplinary school providers to deliver FYF-SB
- Eleven public schools across three public school districts (Cherry Creek School District, Denver Public Schools, Littleton Public Schools) were involved
- 24 students completed FYF-SB
- Student and parent report indicated that significant reductions in anxiety occurred following participation in FYF-SB

Phase 2: (2019-2020)

- A Train-the-Trainer model was implemented in the three districts to train 76 providers across an additional 25 schools
- Over 80 students have enrolled in FYF-SB
- Data collection is underway to examine the effectiveness during this phase of FYF-SB in public schools – results of Phase 2 should be available Fall 2020!

Potential Impact of FYF-SB

- Preliminary results indicated that students displayed significant reductions in anxiety following FYF-SB
- Initial results are promising and suggest that training school providers to deliver FYF-SB can provide access to much needed mental health care for many students with ASD or other social/communication challenges
- Providing evidence-based interventions in schools has the potential to decrease health disparities to the students directly and indirectly involved in the program
- Training natural change agents to deliver the intervention is critical for sustainability

NEW Research!

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 participate in pre- and post assessments and a follow up visit 6 months after the intervention. Children enrolled in the experimental intervention group will receive 12 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 expected to be funded by NIH. COMIRB 19-2717. Cincinnati Children's Hospital sIRB 2016-6954. PI: Jareen Meinen-Derr, PhD, MPH, FACE; Local PI: Deborah Mood, Ph.D. Deborah.Mood@cuanschutz.edu

Once funding is awarded those interested will be contacted with enrollment information.

Dates: 4/1/2020-3/31/2025



**Deborah Mood, PhD
Clinical Psychologist**

Debbie Mood is a licensed psychologist who specializes in working with deaf and hard of hearing children, as well as with children with a variety of developmental disabilities. Her primary appointment within Developmental Pediatrics at Children's Hospital Colorado emphasizes clinical assessment and treatment of developmental disabilities.

Dr. Mood also participates on interdisciplinary teams specifically providing assessment for deaf and hard of hearing children.

Her current applied research and clinical projects focus on improving assessment and intervention practices for deaf/hard of hearing children dually diagnosed with an autism spectrum disorder.



Lorraine Kubicek, PhD
Assistant Professor

Dr. Kubicek has over 30 years of experience conducting both quantitative and qualitative research and evaluation with families (from diverse racial, ethnic, and socioeconomic backgrounds) and their children who are typically developing, at-risk or with special needs. A common theme in her work has been a recognition of the profound effect the quality of parent-child relationships has on the overall health, development and well-being of children and families. Her areas of interest and expertise include infant/early childhood mental health, social-emotional communication, language development, parent-child relationships, and family routines. She has worked in both university and nonprofit settings and has served as the Principal Investigator or Project Director on projects funded by federal, state, and private foundation grants.

NEW Project!

Project SCOPE-National Training Initiative

Our application for funding from the Wyoming Institute for Disabilities for Supporting Children of the Opioid Epidemic (Project SCOPE) was recently approved. The purpose of this national initiative is 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), who are suspected of being impacted by opioid use, trauma, or related exposure.

Core curriculum will include current research on brain development, developmental outcomes of prenatal exposure to opioid and other substances, trauma informed care, provider secondary trauma stress and strategies to support caregivers. This initiative 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.

If you are interested in learning more about Project SCOPE, please contact Lorraine F. Kubicek, PI at Lorraine.Kubicek@cuanschutz.edu.



Project SCOPE:
Supporting Children of the OPIoid Epidemic

JFK Partners Trainees & Fellows 2019-20 Scholarly Projects

JFK Partners has a cohort of 21 long-term interdisciplinary healthcare trainees (over 300 hours) participating in the Leadership Education in Neurodevelopmental Disabilities (LEND) Training program each year.

One of the LEND Program requirements is to complete a year-long scholarly project. It offers fellows the opportunity to explore an area of professional interest in depth and to apply leadership skills in an arena with a broad audience. The project needs to include measureable outcomes and a written product.

At LEND Graduation in May of each year, trainees and fellows present their projects and products developed. Additionally, the projects and products are disseminated in a variety of ways such as at conferences, trainings, family support groups, in journal articles or books and some are posted on the JFK Partners website. Questions about the projects can be directed to Dina Johnson, Training Co-Director at Dina.Johnson@cuanschutz.edu.

Trainee/Fellow Discipline	Project/Description
Bennington, Kait Occupational Therapy	Supporting Families in the Transition from NICU to Home
Croft, Katie Family (Sibling)	Increasing Parent's Understanding of Evidence-Based Interventions to inform Selection Decisions
Engstrom, Erin Psychology	The Relationship between Daily Activities, Quality of Life and Anxiety in Adolescents with Autism Spectrum Disorder and Intellectual Disability
Ennis, Robin Self-Advocacy	Hydrocephalus Awareness
Gerardi, Annelise Audiology	Importance of Relationships Between Signal to Noise Ratio, Auditory Environment, and Hearing Assistive Technology Use in Young Children
Green, Jillian Developmental Beh Pediatrics	Evaluation of the feasibility and effectiveness of ECHO telehealth to provide training in ASD screening/ diagnosis for primary care physicians
Harrison, Caroline Public Health	The potential discrepancy between access to and quality of healthcare among children with versus without various developmental or behavioral symptoms.
Jonnalagadda, Puji Developmental Beh Pediatrics	Identifying Children At-Risk for Learning Disabilities within a Pediatric Clinic
Lattanzi, Kendal Speech-Language Pathology	Exploring the relationship between the development of positive feeding behaviors and expressive/ receptive vocabulary skills in children ages 6-24 monthss
Leavengood, Darby PT	Failure to Thrive: Early Interventionists Play an Important Role
Madore, Kassandra Audiology Nightengale, Emily Audiology	Considerations in Hearing Devise Technology in Children with Developmental Delays
Moore, Jaime Nutrition	Exploring Family and Provider Perspectives to Optimize Obesity Management for Youth with I/DD
Pancoast, Elizabeth Audiology	Loss to Follow-Up: Providing Information to Keep Children from Slipping Through the Cracks
Pickard, Katherine Psychology	Examining the use of evidence-based strategies to support young children at-risk for ASD within the Early Intervention system
Rodriguez Sisneros, Regina Diversity	Person-centered planning with a focus on cultural identities and connections
Rosen, Tamara Psychology	Examining the effect of CBT across traditional and distinct anxiety symptoms in youth with ASD: Three Case Studies from a Facing Your Fears school-based trial
Smith, Isaac Psych Intern	Severity of autistic symptoms as a predictor of treatment response to CBT for anxiety in ASD
Spranger, Zoe Social Work	Barriers & Successes to Family Crisis Plan Implementation
Walker, Katherine Spiritual Care	Spiritual Issues Important to Parents of Children with Disabilities

Developmental Pediatrics / JFK Partners
Peer-refereed journal publications published July 1, 2019 - April 1, 2020

1. **Angulo AS**, Joshi J, Nesin M, Padula MA, Kochhar S, Connery AK. (2019) *Neurodevelopmental delay: Case definition & guidelines for data collection, analysis, and presentation of immunization safety data*. Vaccine, 10;37(52):7623-7641. <https://doi.org/10.1016/j.vaccine.2019.05.027>
2. **Berkovits LD**, Moody CT, 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. <https://doi.org/10.1007/s10803-019-04309-1>
3. Berry-Kravis E, Kidd SA, Lachiewicz AM, Choo TH, **Tartaglia N**, Talapatra D, Aguirre-Kolb C, Andrews H, Riley K. (2019) *Toilet Training in Fragile X Syndrome*. J Dev Behav Pediatr, 40(9):751-761. <https://doi.org/10.1097/DBP.0000000000000735>
4. **Bonino, A.Y.** and **Malley, A.** (2019). *Measuring open-set, word recognition in school-aged children: Corpus of monosyllabic target words and speech maskers*. The Journal of the Acoustical Society of America, 146:EL393-EL398. <https://doi.org/10.1121/1.5130192>
5. Croen LA, Qian Y, Ashwood P, Zerbo O, Schendel D, Pinto-Martin JA, Fallin MD, Levy S, Schieve LA, Yeargin-Allsopp M, **Sabourin KR**, Ames JL. (2019). *Infection and Fever in Pregnancy and Autism Spectrum Disorders: Findings from the Study to Explore Early Development*, Autism Research, 12:1551-1561. <https://doi.org/10.1002/aur.2175>
6. Davis SM, Reynolds RM, Dabelea DM, Zeitler PS, **Tartaglia NR**. (2019) *Testosterone Treatment in Infants With 47,XXY: Effects on Body Composition*. J Endocr Soc. 3(12):2276-2285. <https://doi.org/10.1210/js.2019-00274>
7. **DiGuseppi C**, Sabourin KR*, Levy S, Soke GN, Lee L-C, Wiggins L, Schieve LA. (2019) *Injury-related treatments and outcomes in preschool children with autism spectrum disorder: Study to Explore Early Development (SEED)*. Res Autism Spectr Disord, 66:101413. [epub ahead of print] <https://doi.org/10.1016/j.rasd.2019.101413>
8. Eckert EM, Dominick KC, Pedapati EV, Wink LK, Shaffer RC, Andrews H, Choo TH, Chen C, Kaufmann WE, **Tartaglia N**, Berry-Kravis EM, Erickson CA. (2019) *Pharmacologic Interventions for Irritability, Aggression, Agitation and Self-Injurious Behavior in Fragile X Syndrome: An Initial Cross-Sectional Analysis*. J Autism Dev Disord, 49(11):4595-4602. <https://doi.org/10.1007/s10803-019-04173-z>
9. Hamner T, Hepburn S, Zhang F, Fidler D, **Robinson Rosenberg C**, Robins DL, Lee NR. (2019) *Cognitive Profiles and Autism Symptoms in Comorbid Down Syndrome and Autism Spectrum Disorder*. J Dev Behav Pediatr. [Epub ahead of print] <https://doi.org/10.1097/DBP.0000000000000745>
10. Kramer, J., Schwartz, A.E., Watkins, D., Peace, M., Luteran, S., Barnhart, B., Bouma-Sims, J., Riley, J., Shouseb, J., Maharaj, R., **Robinson Rosenberg, C.**, Harvey, K., Huereña, J., Schmid, K., and Sladen Alexander, J. (2019). *Improving Research and Practice: Priorities for Young Adults with Intellectual/Developmental Disabilities and Mental Health Needs*. Journal of Mental Health Research in Intellectual Disabilities, 12:3-4, 97-125. <https://doi.org/10.1080/19315864.2019.1636910>
11. **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.
12. McCabe KL, Popa AM, Durdle C, Amato M, Cabaral MH, Cruz J, Wong LM, Harvey D, **Tartaglia N**, Simon TJ. (2019) *Quantifying the resolution of spatial and temporal representation in children with 22q11.2 deletion syndrome*. J Neurodev Disord, 11(1):40. <https://doi.org/10.1186/s11689-019-9301-1>

Developmental Pediatrics / JFK Partners
Peer-refereed journal publications published July 1, 2019 - April 1, 2020

13. **McTee, H.M., Mood, D.,** Fredrickson, T., Thrasher, A., and **Bonino, A.Y.** (2019). *Using Visual Supports to Facilitate Audiological Testing for Children with Autism Spectrum Disorder*. American Journal of Audiology, 28:4, 823-833. https://doi.org/10.1044/2019_AJA-19-0047
14. Maenner, MJ, Shaw, KA, Baio, J, Washington, A, Patrick, M, DiRienzo, M, Christensen, DL, Wiggins, LD, Pettygrove, S, Andrews, JG, Lopez, M, Hudson, A, Baroud, T, Schwenk, Y, White, T, **Robinson Rosenberg, C**, Lee, LC, Harrington, RA, Huston, M, Hewitt, A, Esler, A, Hall-Lande, J, Poynter, JN, Hallas-Muchow, L, Constantino, JN, Fitzgerald, RT, Zahorodny, W, Shenouda, J, Daniels, JL, Warren, Z, Vehorn, A, Salinas, A, Durkin, MS, Dietz, PM (2020). *Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2016*. Surveillance Summaries, 69(4);1–12. <http://dx.doi.org/10.15585/mmwr.ss6904a1>.
15. Monteiro SA, **Dempsey J**, Berry LN, Voigt RG, Goin-Kochel RP. *Screening and Referral Practices for Autism Spectrum Disorder in Primary Pediatric Care*. Pediatrics. 2019 Oct;144(4). <https://doi.org/10.1542/peds.2018-3326>
16. **Pickard, K. Blakeley-Smith, A.,** Boles, R., Duncan, A., Keefer, A., O’Kelly, S., & **Reaven, J.** (2020). *Examining the sustained use of a cognitive behavioral therapy program for youth with ASD and co-occurring anxiety*. Research in Autism Spectrum Disorders. 73:101532. <https://doi.org/10.1016/j.rasd.2020.101532>
17. **Reaven, J., Reyes, N., Pickard, K., Tanda, T.,** & Morris, M. A. (2019). *Addressing the Needs of Diverse Youth with ASD and Anxiety in Public Schools: Stakeholder Input on Adaptations of Clinic-Based Facing Your Fears*. School Mental Health, 1-15. <https://doi.org/10.1007/s12310-019-09351-z>
18. **Reyes, N., Pickard, K., & Reaven, J.** (2019). *Emotion regulation: A treatment target for Autism Spectrum Disorder*. The Bulletin of the Menninger Clinic, 83(3):205-234. <https://doi.org/10.1521/bumc.2019.83.3.205>
19. **Reynolds, AM,** Connolly, HV., **Katz, T.,** Goldman, SE., Weiss, SK., Halbower, AC., Shui, AM, Macklin, EA, Hyman, SL, & Malow, BA. (2020). *Randomized, Placebo-controlled Trial of Ferrous Sulfate to Treat Insomnia in Children with Autism Spectrum Disorders*. Pediatric Neurology. 104:30-39. <https://doi.org/10.1016/j.pediatrneurol.2019.07.015>
20. Shaw, KA, Maenner, MJ., Baio, J; Washington, A. ; Christensen, DL., Wiggins, LD, Pettygrove, S., Andrews, JG, White, T, **Rosenberg, CC**, Constantino, JN, Fitzgerald, RT, Zahorodny, W, Shenouda, J, Daniels, JL, Salinas, A, Durkin, MS, Patricia M. Dietz, DrPH. (2020). *Early Identification of Autism Spectrum Disorder Among Children Aged 4 Years — Early Autism and Developmental Disabilities Monitoring Network, Six Sites, United States, 2016*. Surveillance Summaries, 69(3);1–11. <http://dx.doi.org/10.15585/mmwr.ss6903a1>.
21. **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*. Am J Med Genet A., 182(2):386-396. <https://doi.org/10.1002/ajmg.a.61439>
22. Wiggins L, **DiGuseppi C,** Schieve L, Moody E, Soke GN, Giarelli E, Levy S. (2020). *Wandering Among Preschool Children with and Without Autism Spectrum Disorder*. J Dev Behav Pediatr 2020 00:1-7. DOI: [10.1097/DBP.0000000000000780](https://doi.org/10.1097/DBP.0000000000000780)

University of Colorado School of Medicine, Developmental Pediatrics/JFK Partners Research Studies

Recruitment: These are ongoing projects, but due to COVID-19, many aspects of research may be temporarily suspended.

If you are interested in one of the research projects, email the listed contact for more information.

Study	Purpose	Eligibility	Contact
Virtual and Augmented Reality Treatment of Fear of Spiders and Insects in Children with Autism Spectrum Disorder COMIRB#: 18-1914 Funded By: National Science Foundation Site Principal Investigator: Jack Dempsey, Ph.D	The purpose of this study is to pilot the use of an augmented-reality (e.g., Pokémon Go™, Snapchat™) system to treat fear of spiders and insects in children with Autism Spectrum Disorder as state-of-the art system will be an improvement an order virtual-reality based system currently in use for this purpose by the National Health Service of the United Kingdom.	Diagnosed with Autism Spectrum Disorder 2. Can communicate in complete sentences 3. Age 7-13 4. Has a fear of spiders or insects that causes significant anxiety	Jenifer Sargent e-mail: Jenifer.Sargent@childrenscolorado.org Phone number: 720-222-4719
Efficacy of Crisis Plans for Individuals with Neurodevelopmental and Behavioral Dual Diagnosis COMIRB #: 17-0845 Principal Investigator: Cordelia Robinson Rosenberg, PhD, RN <i>Recruitment begun on June 2017 and will end once 200 participants will be enrolled.</i>	The primary objective of this study is to determine if families will adhere to a Crisis Plan, and, if followed, if the Crisis Plan is effective in decreasing occurrence of crises, crisis severity, and emergency service utilization.	We are enrolling the parent of an individual with both a neurodevelopmental diagnosis AND a psychiatric or behavioral diagnosis, and adult individuals with a dual diagnosis. 1) Study partner or legal guardian of individual between 5 - 65 years of age who lives in Colorado and who has both a neurodevelopmental diagnosis AND a psychiatric diagnosis or history of severe challenging behaviors. 2) Individual with a dual diagnosis between 18 - 65 years of age who lives in Colorado and enrolls with a study partner or legal guardian. 3) Study partner, parent or caregiver of individual with a dual diagnosis must be willing/able to complete the Crisis Plan and follow up surveys. 4) Individual with a dual diagnosis must have experienced one or more of the following events: (a) 911 call; (b) Emergency Department admission for mental health reasons or challenging behavior; or (c) requires physical restraint or seclusion to manage challenging behaviors.	Obinna Diala E-mail: obinna.diala@cuanschutz.edu Phone: 303-724-0473

Study	Purpose	Eligibility	Contact
<p>Study to Explore Early Development (SEED): Phase 3</p> <p>COMIRB #: 16-1985 Principal Investigator: Cordelia Robinson Rosenberg, PhD, RN</p> <p>Study dates: 7/1/2016-6/30/2021</p>	<p>The Study to Explore Early Development (SEED III) is a multi-year study to help identify factors that may put children at risk for autism spectrum disorders (ASDs) and other developmental disabilities.</p>	<p>By invitation only, we are enrolling children:</p> <ol style="list-style-type: none"> 1. Born in and currently live in one of the eight SEED study counties. 2. Between the ages of 2-5. <p><i>Many different children are eligible to take part in SEED including:</i></p> <ul style="list-style-type: none"> • Children with ASDs • Children with other developmental disabilities • Children without developmental disabilities 	<p>Kristina Hightshoe, MSPH E-mail: Kristina.Hightshoe@ucdenver.edu Phone: 303-724-7672</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 Principal Investigator: Nicole Tartaglia, MD, MS</p> <p>Co-Investigators: Shanlee Davis, MD; Rebecca Wilson, PsyD, and Jen Janusz, PsyD</p> <p>Study dates: September 2017 – August 2022</p> <p>Study website: https://clinicaltrials.gov/ct2/show/NCT03396562</p>	<p>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.</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, XYY or other sex chromosome variation 3. Additional screening criteria to discuss with staff 	<p>E-mail: extraordinarykids@ucdenver.edu Phone: 720-808-0873</p>
<p>Hearing Assessment for Children with Developmental Disabilities</p> <p>CU Boulder IRB #: 16-0639 Principal Investigator: Angela Yarnell Bonino, Ph.D., CCC-A Co-investigators: Debra Mood, Ph.D. and Eric Vance, Ph.D.</p> <p>Funding Source: American Speech-Language-Hearing Foundation</p> <p>Study Dates: 2019-2023</p>	<p>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.</p>	<ol style="list-style-type: none"> 1. 2 to 5 years of age 2. A diagnosed developmental difference of one of the following: (a) delay in at least one area of development (language, cognition, motor, or social/emotional); (b) autism spectrum disorder; or (c) Down syndrome. 3. No known permanent hearing loss. 4. Negative history for placement of pressure equalization (PE) tubes or other ear surgery. 5. Additional screening criteria regarding child's development. 	<p>Email: childhear@colorado.edu Phone: 303-735-6252 Website: https://www.colorado.edu/lab/chapl/</p>

Study	Purpose	Eligibility	Contact
<p>Improving Outcomes Using Augmentative and Alternative Communication for Children Who are Deaf or Hard of Hearing: A Technology-Assisted Language Intervention Randomized Control Trial</p> <p>PI: Deborah Mood, PhD Award: 1R01DC018550 4/1/20-3/31/25</p> <p>This study is expected to be funded by NIH. COMIRB 19-2717. Cincinnati Children's Hospital sIRB 2016-6954</p> <p>Dates: 4/1/2020-3/31/2025</p>	<p>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.</p>	<p>Children who are between the ages of 3-10 years old who have a permanent bilateral hearing loss (clinical severity between moderate and profound) and who have language delay or a gap between their language skills and their nonverbal ability may be appropriate for the study.</p> <p>All children will participate in pre- and post assessments and a follow up visit 6 months after the intervention. Children enrolled in the experimental intervention group will receive 12 weeks of weekly speech/language therapy (1 hour/week).</p> <p>Following participation in the study, those who were not assigned to the technology group may choose to participate in the intervention.</p>	<p>Dr. Deborah Mood Email: Deborah.Mood@cuanschutz.edu</p>
<p>Descriptive Prospective Pilot Study of Severely Obese Adolescents/Young Adults with Intellectual Disability Presenting for Bariatric Surgery Evaluation</p> <p>COMIRB#: 17-1919 <i>Principal Investigator:</i> Jaime Moore, MD</p> <p>Study Dates: 2018-2020</p>	<p>The purpose of the project is to determine the psychosocial and health characteristics of severely obese adolescents and young adults with intellectual disability, who present to Children's Hospital Colorado's (CHCO) Bariatric Surgery Center for weight loss surgery evaluation. Additionally, we aim to determine if these pre-operative characteristics are associated with a) completing vs. not completing the pre-operative process and b) for those who undergo surgery, post-operative psychosocial and health-related outcomes.</p>	<p>Patients between 10-25 years old seen in the CHCO Bariatric Surgery Center who have a documented history of intellectual disability will be approached for study enrollment.</p> <p>If there is no previously documented history of intellectual disability, but during the routine evaluation of the patient in the bariatric surgery clinic, there is a clinical suspicion that the patient may have intellectual disability, the teams' clinical psychologist will administer brief screens for intellectual and adaptive functioning to help determine study eligibility.</p>	<p>Dr. Jaime Moore Phone: 303-724-8419 Email: Jaime.Moore@CUAnschutz.edu</p>
STUDIES COMING SOON!			
<p>CASCADE Study: Cannabidiol (CBD) Study in Children with Autism Spectrum Disorder</p> <p><i>Principal Investigator:</i> Nicole Tartaglia, MD <i>Funding Source:</i> Colorado Department of Health and Environment (CDPHE)</p> <p>Study Dates: 2020-2022</p>	<p>This study is a placebo-controlled clinical trial of CBD in children age 5-17 with autism spectrum disorder evaluating the effect of CBD on symptoms of irritability, aggression, anxiety and social behaviors.</p>	<p>Approvals for this study are currently underway.</p>	<p>Official recruitment has not yet begun.</p> <p>Interested parties should email: CBDiAutismStudy@childrenscolorado.org with their contact information. We will contact you once study approvals are completed.</p>



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COVID-19 Resources

Faculty, Staff and Fellows at Developmental Pediatrics and JFK Partners created a Resource list specific for caring for individuals with disabilities during the COVID-19 quarantine. They are posted on our website here: <https://tinyurl.com/DP-JFK-COVID19>.

Upcoming Opportunities

JFK Partners 8th Annual
Autism Spectrum Disorder Conference

Shining a Light on Mental Health in ASD Across the Lifespan

Friday, Oct 9, 2020
8:00 AM - 4:30 PM

Anschutz Medical Campus

Registration begins July 2020
www.JFKPartners.org

*The conference will take place using state and university COVID-19 policies and guidelines for Oct events.

Please be on the lookout for our next Research Newsletter in the Fall of 2020. 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/2020SpringNews>.

Connect with Us

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@CUAnschutz.edu.



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