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Developmental Pediatrics

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## Research Newsletter Fall 2021

Dear Community Partners,

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

We never could have predicted one year ago, that as a community and a country, we would still be in the throes of the COVID-19 pandemic. Although much progress has been made in the fight against COVID-19, the significant impacts of the pandemic continue to be felt. In spite of these challenges, our faculty has been busy writing grants and publishing our findings on topics of great import to individuals with disabilities and their families

[Spotlight!](#) In this issue, we are so pleased to be highlighting the work of Ann Reynolds, MD, Medical Director, Developmental Pediatrics, Professor of Pediatrics at the University of Colorado School of Medicine. Dr. Reynolds has made important contributions to our understanding of medical conditions that co-occur in autism spectrum disorder and has been an important member of our leadership team since 2000.

[New Grants](#) Faculty have been busy seeking new research opportunities. Check out this section for updates!

[Studies Recruiting](#) Don't miss our Recruitment Section where we list research projects that are actively recruiting individuals for participation.

[Updates](#) Check out the research update section for current updates on the

[Recent Publications](#) We have included a list of recent publications at the end of this newsletter.

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 feedback here:

<https://www.surveymonkey.com/r/ResearchNews2021>.

Warmly,

*Judy Reaven, PhD*

Director of Research, JFK Partners & Developmental Pediatrics

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## Faculty Spotlight



Ann Reynolds, MD

Medical Director, Developmental Pediatrics

Professor of Pediatrics

University of Colorado Anschutz Medical Campus

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

I always liked science. I did a student research fellowship between my first and second year of medical school. When I came to Denver, my clinical focus changed from children born prematurely to autism. I found it very frustrating that there was very little known about how to help children with autism who had sleep problems. When I joined the Study to Explore Early Development (SEED) in 2001, I worked hard to ensure that we included data collection about sleep

**What is your area of research?**

My research has primarily focused on medical conditions associated with autism and/or other developmental delays. Most of the research projects that I have participated in have evaluated the prevalence, treatment, or associations with sleep, gastrointestinal and nutrition problems in children with autism.

**Current project and practical implications?**

I am currently working on developmental, behavioral and medical issues associated with sleep problems and perinatal risk factors for gastrointestinal symptoms in children 2 to 5 years of age. I also plan to start working on a project evaluating polygenic risk score for sleep problems in children with autism. Practical implications include ensuring that medical providers recognize sleep and gastrointestinal issues in children with autism and other developmental delays, and that the two are often associated with each other. The hope is that this will lead to better treatment of these issues. I also feel that better understanding of sleep, gastrointestinal, and nutrition problems will lead to better treatments in the future.

1. Reynolds A, Krebs NF, Stewart PA, Austin H, Johnson SL, Withrow N, Molloy C, James SJ, Johnson C, Clemons T, Schmidt B, Hyman SL. Iron status in children with autism spectrum disorder. *Pediatrics*. 2012 Nov;130 Suppl 2:S154-9. [PMID: 23118246](#)
2. Malow BA, Adkins KW, Reynolds A, Weiss SK, Loh A, Fawkes D, Katz T, Goldman SE, Madduri N, Hundley R, Clemons T. Parent-based sleep education for children with autism spectrum disorders. *J Autism Dev Disord*. 2014 Jan;44(1):216-28. [PubMed PMID: 23754339](#)
3. Malow BA, Connolly HV, Weiss SK, Halbower A, Goldman S, Hyman SL, Katz T, Madduri N, Shui A, Macklin E, Reynolds AM. The Pediatric Sleep Clinical Global Impressions Scale-- A new tool to measure pediatric insomnia in autism spectrum disorders. *J Dev Behav Pediatr*. 2016 Jun;37(5):370-6. [PMID: 27244298](#)
4. Reynolds AM, Soke GN, Sabourin KR, Hepburn S, Katz T, Wiggins LD, Schieve LA, Levy SE. Sleep Problems in 2- to 5-Year-Olds With Autism Spectrum Disorder and Other Developmental Delays. *Pediatrics*. 2019 Mar;143(3). doi: 10.1542/peds.2018-0492. [PubMed PMID: 30745433](#). Video abstract: <https://pediatrics.aappublications.org/content/143/3/e20180492.long>
5. Reynolds AM, Soke GN, Sabourin KR, Croen LA, Daniels JL, Fallin MD, Kral TVE, Lee LC, Newschaffer CJ, Pinto-Martin JA, Schieve LA, Sims A, Wiggins L, Levy SE. Gastrointestinal Symptoms in 2- to 5-Year-Old Children in the Study to Explore Early Development. *J Autism Dev Disord*. 2021 Jan 4; doi: 10.1007/s10803-020-04786-9. [Epub ahead of print] [PubMed PMID: 33394243](#).

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## New Grants

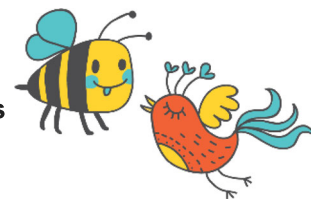
**New Grant! Group Cognitive Behavioral Treatment for Anxiety in Adolescents with Autism and Intellectual Disability: A Randomized Controlled Trial**

and their parents learn skills to support anxiety management and build coping skills and brave behavior. It is a family-focused, group treatment. Teens between the ages of 12-18 who have Autism, Intellectual Disability, and anxiety are eligible for participation. Families will participate in assessments and will either enter the CBT treatment group immediately or within 6-months of joining the study. The grant will run from September 2021-August 2024. Please reach out to [fystudy@ucdenver.edu](mailto:fystudy@ucdenver.edu) to enroll or ask further questions about the study. This study is funded by the Department of Defense. Recruitment information can be seen in the [next section](#).

Other participating JFK Partners/Developmental Pediatrics Faculty: Richard Boles, Lisa Hayutin, Allison Meyer, Caitlin Middleton, Nuri Reyes, and Judy Reaven.

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**New Grant! The Birds and Bees: A pilot study of a parent-mediated sexuality education program for preteens and teens on the Autism Spectrum**



Principal Investigator: Lindsey DeVries, PhD and Co-PI: Caitlin Middleton, PhD

Youth with autism spectrum disorder (ASD) often experience challenges navigating puberty, sexuality, and relationship changes that often occur in adolescence. Parents of preteens and teens with ASD frequently feel ill-equipped to provide proactive teaching and support to their child around puberty, caring for changing bodies, sexuality, and relationships. To date, there are very few interventions and supports that provide specific information and resources for parents in supporting their autistic children through puberty and adolescence. The purpose of the study is to evaluate the feasibility and initial efficacy of the Birds and Bees Program, a parent-mediated sexual and reproductive health program for youth with ASD. We are seeing parents of kids ages 10-18. Interested parents can call 720-777-6630 to get on the list for Birds and Bees. This project is funded by the Autism Intervention Research Network on Physical Health (AIR-P). This project is working on COMIRB approval.

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**New Grant! Specialty Neurodevelopmental Care for Adults with Autism Spectrum Disorder – What Works?**

Principal Investigator: Jessi Solomon Sanders, MD

Increasing numbers of youth with Autism Spectrum Disorder (ASD) are becoming adults each year; however, most neurodevelopmental specialists practice in pediatric settings. Adults with ASD often have more negative experiences with, or lack of access to, healthcare. Dr. Sanders recently created a new consultation clinic for adults with ASD and other developmental disabilities (DD) in the University of Colorado Adult Behavioral Neurology Clinic.

Interviews will be conducted with a sample of adults with ASD and their families/caregivers who are patients of Dr. Sanders' clinic. The study will evaluate priorities, expectations, and needs for adult models of neurodevelopmental specialty care. We will also perform chart

We expect to better understand the patient-and family-perceived value of this clinic, patient and family priorities, and the barriers they face obtaining high-quality healthcare. Results from this pilot will serve as the basis for larger-scale studies to support building more effective patient-centered programs, investigating health outcomes, and addressing barriers to equitable, accessible healthcare for adults with ASD.

This project is funded by the Autism Intervention Research Network on Physical Health (AIR-P). COMIRB 21-2849.



### **New Grants! Study to Explore Early Development (SEED) Follow Up Studies**

PI (Component A): Carolyn DiGuseppi, MD, PhD

PI (Component B): Cordelia Robinson Rosenberg, PhD, RN

Other participating JFK Partners/Developmental Pediatrics personnel: Brian Be, Tessa Crume, Sandra Friedman, Kristina Hightshoe, Nuri Reyes, Ann Reynolds, Steve Rosenberg, Jessica Sanders, Sarah Schmiede

The Colorado School of Public Health and the School of Medicine JFK Partners/Developmental Pediatrics are excited to announce that a new research project has been funded.

**Component A – Enhanced Epidemiologic Research and Participant Follow-Up Surveys:** The study will continue the work of previous SEED studies. Families enrolled in SEED Phases 1-3 will be contacted to answer questions about genetic, prenatal, early-life and family factors that contribute to autism spectrum disorder (ASD). The study will also look at differences and similarities in the behaviors, abilities, and health of young children with ASD. It will also provide insights into the experiences of adolescents with ASD as they mature through adolescence and into adulthood. The grant for Component A will run from July 2021 – June 2026. IRB has not yet been finalized.

**Component B – In-Person Assessment of Intellectual Abilities of SEED Participants:** The purpose of this study is to gain knowledge about the functioning of individuals with ASD through follow-up assessments of SEED 1-3 participants. This study will evaluate the reliability of childhood measures of intellectual status by comparing SEED participants' current functioning (aged 8 to 22) with their abilities when they were preschoolers. These data will be used to examine factors that affect the stability of intellectual status, and its ability to predict transition outcomes. The grant for Component B will run from July 2021 – June 2025. Grant Funder: Centers for Disease Control and Prevention. For more

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## Studies Recruiting

### **Group Cognitive Behavioral Treatment for Anxiety in Adolescents with Autism and Intellectual Disability: A Randomized Controlled Trial**

#### **What is the study about?**

This research study will investigate a Cognitive Behavior Therapy (CBT) group treatment to determine if it is more effective than therapy services that adolescents with ASD and intellectual Disability (ID) are already receiving at school, in the community, or from their doctor. This CBT intervention has been adapted for the learning and language needs of teens with Autism and ID.

#### **What would I have to do?**

1. Participants may enter the 14-week group within 6 months of consent
2. Current therapies will be tracked
3. Teens and a caregiver will participate in a 14-week therapy program
4. Families will complete assessments before the 14-week therapy program and up to 6 months after completing the program

#### **Is this study right for me and my child?**

Is your child between 12-18 years of age and does your child have: 1. Autism spectrum disorder, 2. Intellectual disability, and 3. Anxiety (fears or worries) and/or Emotion regulation difficulties? If you answered YES, then you and your child may qualify for this study. Please note that participation is voluntary and you will be compensated for your participation.

COMIRB#20-3142 PI: Audrey Blakeley-Smith, PhD

**For more information, please contact:** [fyfstudy@ucdenver.edu](mailto:fyfstudy@ucdenver.edu)

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### **Technology-Assisted Language Intervention (TALI) for children who are deaf and hard of hearing**

(COMIRB #19-2717)

Deborah Mood, Ph.D., site PI, University of Colorado Denver.

Jareen Meizen-Derr, Ph.D., PI Cincinnati Children's Hospital

#### **What is the goal of the study?**

We would like to see whether children who are deaf and hard of hearing make more progress with their language development with traditional speech/language therapy, or with speech-language therapy assisted by technology, specifically use of an Augmentative and Alternative Communication (AAC) program.



- Children must be currently enrolled in speech/language therapy or willing to start speech/language therapy when they enter the study.
- Caregivers must have spoken language goals for the child.
- Children CAN use both sign language and spoken English.
- Caregivers must be able to participate in the treatment in spoken English.

### How do I find out more about the study?

Please email [tali@ucdenver.edu](mailto:tali@ucdenver.edu) or call 720-777-2778 (and select option 2)

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## Updates

### Dissemination and Implementation of Stroke Prevention Looking at the Care Environment (DISPLACE)

Sickle cell anemia (SCA), an inherited blood disorder, is the most common cause of stroke in children. For children with SCA ages 2 to 16, we have a screening tool to detect stroke risk called transcranial Doppler or TCD. A TCD tells us how quickly the blood is flowing in a child's brain and can alert us to children who are at high risk for stroke. Once a child is found to be at risk, we can start treatments that can help to prevent the stroke from happening. Unfortunately, TCD is not universally used in the United States, despite clear guidelines telling doctors how to use it for children with SCA. The goal of the DISPLACE study is to figure out how many children are missing TCD, the things that help or make it harder to get TCD, and to find ways of helping children with SCA to get this important screening.

#### Below are key findings from DISPLACE so far:

- Many children with SCA are not receiving TCD (screening rates ranged from 31% to 75% across sites, with an average of only 50%).
- Families find the name TCD to be difficult to understand and both families and medical providers tell us that education and information are very important.
- Medical providers tell us that problems tracking families with missed appointments is a challenge, and families and medical providers tell us that difficulties with care coordination get in the way of TCD. They feel that supports that address these challenges will help to improve TCD screening rates.
- Interventions that help with education (including a new term "Sickle Stroke Screen"), patient tracking, and care coordination are currently being used to see if rates of TCD screening can be improved. Below is an example of a rebranded logo and infographic that are currently be used with an educational pamphlet as part of these interventions. We have published several papers from DISPLACE so far for those who would like more information.
- We also strongly recommend a recent article from the NY Times that highlights the impact of stroke and the importance of screening for stroke risk in children with SCA: <https://www.nytimes.com/2021/05/23/health/sickle-cell-black-children.html>.

DISPLACE (NIH R01 HL133896) is an ongoing, large, 28-site study led by Julie Kanter, MD (University of Alabama at Birmingham), Robert Adams, MD, MS (Medical University of South Carolina), and Cathy

South Carolina), and Martina Mueller, PhD (Medical University of South Carolina) are co-investigators. Children's Hospital Colorado was one of the 28 sites that participated in DISPLACE under principal site investigator, Rachelle Nuss, MD (Director of the Colorado Sickle Cell Treatment and Research Center). IRB protocol numbers are Pro00080391 and Pro00073134.

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**Increasing Statewide Access to Expert, Interdisciplinary  
Training on the Impacts of the Opioid Crisis: Project SCOPE  
(Supporting Children of the Opioid Epidemic)**

Lorraine F. Kubicek, PhD, IMH-E © Research Mentor, Abigail Angulo, MD, Renee Charlifue-Smith, MA, CCC-SLP, and Melissa Argenti, MS OTR/L

Project SCOPE is a national training initiative lead by the Wyoming Institute for Disabilities in partnership with the Nisonger Center at Ohio State and the University of Cincinnati Center for Excellence in Developmental Disabilities through funding from the Administration for Community Living, HHS.

SCOPE's purpose is to train on evidence-based practices in screening, monitoring, and interdisciplinary care for young children and families impacted by Neonatal Abstinence Syndrome (NAS), Neonatal Opioid Withdrawal Syndrome (NOWS), opioid use, trauma, or related exposure. Training uses the ECHO (Extension of Community Healthcare Options) ® model, an "all teach-all learn" model that includes case-based learning led by expert teams through videoconferencing. All sessions are free. The goal is to reduce health disparities in remote and traditionally underserved communities by closing gaps in access to training and delivery of services. The curriculum includes:

- current research on brain development
- developmental outcomes (e.g., emotional development, language development, sensory concerns) of prenatal exposure to opioids and other substances
- trauma-informed care
- provider secondary trauma stress
- strategies to support caregivers

Colorado was among the first states awarded SCOPE funding, and the response to our initial series last spring was overwhelmingly positive from the multidisciplinary group of attendees working in over 50 different zip codes in the state. Between 92 to 100% "agreed" or "strongly agreed" that the training was useful, relevant, and contributed to their understanding of strategies to support children impacted by the opioid crisis. Over 100 parents and professionals have registered for our second series began September 17,



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**Improving Youth SSI Recipients' Employment Outcomes  
through an Integrated Treatment Team Intervention in a Healthcare Setting**

Aryn Taylor, PhD, CRC., Teresa Nguyen, MPH, Melanie Honsbruch, CPWIC

The goal of the project was to create a proposed intervention for federal partners to help youth Supplemental Security Income (SSI) recipients gain employment. There are very few models that integrate employment resources with healthcare for youth patients who are receiving SSI. Children's Hospitals and clinics are trusted setting for patients and their families and offer the opportunity to integrate employment supports to assist with transition. Integrating employment supports with health care is feasible and may benefit youth SSI recipients gain employment. Youth and families want greater collaboration between medical providers and employment supports so they are navigating few systems to access to services and assistance. Employment is a pathway to independence, community connections, financial stability and social networking for youth with disabilities. There are many work incentives for youth SSI recipients and they can receive assistance to understand the interaction between work and public assistance benefits like Medicaid and SSI. Receiving this information in a trusted health care setting with the support of their medical providers is an innovative model. Press release:

<https://www.dol.gov/agencies/odep/program-areas/individuals/youth/ssi-youth>

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**Living on versus off-campus:  
An evaluation of campus participation for students  
with intellectual and developmental disabilities enrolled  
in inclusive higher education**

Aryn Taylor, PhD, CRC. and Cordelia Robinson-Rosenberg, PhD, RN

The goal of the study was to evaluate campus participation and educational outcomes for students with intellectual and developmental disabilities (IDD) in inclusive higher education. Students with IDD living on and off-campus participated in campus activities at similar rates. Their educational outcomes were also similar. Students who were their own guardian were more likely to live independently on-campus. COVID-19 had an impact on inclusive higher education programs and reduced the number of hours students with IDD engaged in campus participation activities. Their grades and completion of credit hours were still high during semesters impacted by COVID-19. However, their type of housing (living on-campus or off-campus) did not impact campus participation or educational outcomes. Independent living is desired by a majority of youth and adults with IDD. Inclusive higher education programs that have both on and off-campus housing offer students with IDD the opportunity to live independently. Additional research is needed to understand how inclusive higher education programs can support independent living and integration. University of Arizona IRB# 21-03593873.

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



The primary purpose of this project is to increase awareness, screening and identification and treatment of mental health conditions in children and adolescents with ASD.

Two main activities have occurred towards this effort:

- 1) the completion of a survey to parents, professionals and self-advocates to identify the most common mental health symptoms in youth with ASD, age of identification and common treatments for these symptoms in youth with ASD; and
- 2) to create two information sheets on mental health symptoms in youth with ASD, one for parents and one for providers. Hallee Reynolds, MSW, Sarah McSwegin, LCSW, and Tammy Rosen, Ph.D. partnered in the creation of the information sheets.

The results of the survey (N=88 participants) yielded several main findings:

1. The most common mental health concerns were the presence of anxiety and worries; problems with attention and concentration; and outbursts and meltdowns.
2. The most common age of identification of mental health symptoms was between 6-9 years old and parents and teachers were noted to be most likely to notice these symptoms. Children with ASD and mental health symptoms are likely to receive medications, behavior therapy and/or cognitive behavior therapy.

Participants indicated that children between the ages of 6-9 are most likely to receive mental health services in schools, rather than through other community agencies.

There are many barriers to the identification and treatment of mental health symptoms including:

- lack of trained providers,
- the family's financial situation,
- and the inability for providers to distinguish mental health symptoms from ASD symptoms.

Suggestions for next steps included parent and provider education, and provision of support to school providers.

**Exciting News!** This project has been funded for another year (September 1, 2021 – August 31, 2022).

## Parent Information Sheet

## Provider Information Sheet

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### Recent Publications

#### **Selected Articles**

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

##### **Diagnosis and Workup of Intellectual Disability in Adults: Suggested Strategies for the Adult Neurologist**

###### **What was the goal of this study?**

Knowing the cause of a person's intellectual disability may allow for better medical care and surveillance/prevention of potential disorder complications.

###### **What is done in this study:**

Our proposed diagnostic algorithm can be adapted to any adult with intellectual disability in whom the initial clinical assessment did not lead to an explanation of the person's intellectual disability. Detailed pretest counseling involving the patient and their caregivers should be emphasized. Testing should include either chromosomal microarray with Fragile X testing, or, if available, exome sequencing (ES) with copy number variants and Fragile X testing. Metabolic testing, brain MRI, and EEG should be obtained based on clinical findings.

Frueh JS, Press DZ, Sanders JS. Diagnosis and Workup of Intellectual Disability in Adults: Suggested Strategies for the Adult Neurologist. *Neurol Clin Pract*. August 2021;10.[1212/CPJ.0000000000001128](#).

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##### **Development and application of an ethical framework for pediatric metabolic and bariatric surgery evaluation**

###### **What was the goal of this study?**

Our primary goal was to develop and apply an ethical process to evaluate children with severe obesity considering surgery who also have an intellectual or developmental disability (IDD) or may be preadolescent.

###### **What did we find?**

Ethically grounded guidelines were created to support health care providers during evaluations for surgery to treat severe obesity with children who also have IDD or younger than typical patients. The clinical concerns and related ethical questions that may result during this process were described with discussions on how to resolve.

intellectual impairments or other disabilities can be ethically evaluated by health care teams for surgery. The creation of clear guidelines, a clinical pathway, and the coordination of clinical providers with an ethics team provides an opportunity to ensure all individuals are treated fairly.

### **Why is this important?**

A standardized, ethical approach to evaluate patients with severe obesity and IDD for surgery can help reduce bias against individuals with disabilities and ensure this treatment can be accessible to all individuals who may benefit from it.

Moore JM, Glover JJ, Jackson BM, Coughlin CR 2nd, Kelsey MM, Inge TH, Boles RE. Development and application of an ethical framework for pediatric metabolic and bariatric surgery evaluation. *Surg Obes Relat Dis*. 2021 Feb;17(2):425-433. doi: [10.1016/j.soard.2020.09.014](https://doi.org/10.1016/j.soard.2020.09.014).

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## **Factors that May Influence the Social Communication Questionnaire (SCQ): An Examination of the Spanish and English SCQ in School-Aged Students**

### **What is the goal of this study?**

The goal of this study was to examine child and family factors that may impact SCQ in English- and Spanish-speaking families. A total of 199 English- or Spanish-speaking mothers completed the SCQ.

### **What did we find?**

Results from this study indicated that Spanish-speaking mothers with limited educational attainment were more likely to report higher scores on the SCQ than those with higher educational attainment. Moreover, differences in response patterns were also observed between Spanish- and English-speaking mothers. That is, SCQ scores tended to be influenced by maternal education in the Spanish-speaking sample and by teachers' reports of behavior/emotional problems in the English-speaking sample.

### **Why is this important?**

These findings suggest that when using the SCQ, researchers, clinicians, and school providers 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 factors unrelated to autism symptoms, such as child and family characteristics.

Reyes, N. M., Moody, E., Hightshoe, K., Davidon, S., Rosenberg, S., Dahl, E., & Kubicek, L. F." (In Press). Factors that May Influence Social Communication Questionnaire (SCQ) Scores: An Examination of the Spanish and English SCQ in School-Aged Students. *School Psychology Review*. DOI: [10.1080/2372966X.2021.1927830](https://doi.org/10.1080/2372966X.2021.1927830)

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## **Increasing Access and Reach: Implementing School-Based CBT for Anxiety in Students with ASD or Suspected ASD**

### **What problem are we studying?**

Youth with ASD are at high risk for developing anxiety symptoms that interfere with day-to-

access are even more pronounced for youth from historically underserved backgrounds (e.g., students of color; students from low-income households).

### What is the purpose of the study?

The primary purpose of the current study was to train interdisciplinary school providers to deliver the Facing your Fears-School Based (FYF-SB) program to students with ASD, or suspected ASD and anxiety.

### How did we complete the study?

Twenty-five school providers from 9 diverse elementary/middle schools in the Denver Metro area were trained to deliver FYF-SB. Twenty-nine students (8-14 years old) participated. Eight of 9 schools completed the intervention.

### What did we find?

School providers reported that FYF-SB was feasible and appropriate for students. Parents and students reported significant decreases in student anxiety following participation in FYF-SB, suggesting that historically underserved students with ASD or suspected ASD and anxiety may be able to access mental health interventions in their own schools with good success.

COMIRB#: 18-0114 HRSA R41 MC31075-01-00 (Reaven: PI)

Reaven, J., Meyer, A.T., Pickard, K.\*, Boles, R., Hayutin, L., Middleton, C., Reyes, N., Hepburn, S., Tanda, T., Stahmer, A., & Blakeley-Smith, A. (in press). Increasing Access and Reach: Implementing School-Based CBT for Anxiety in Students with ASD or Suspected ASD. Evidence-based practice in child and adolescent mental health. <http://dx.doi.org/10.1080/23794925.2021.1941430>.

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