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Inside the Institute

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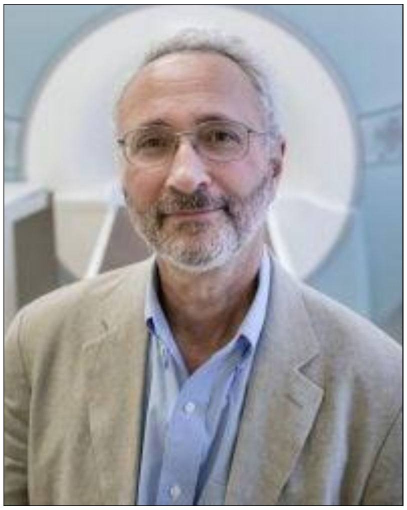
CIDD Director, Dr. Joseph Piven, Earns Prestigious Lifetime Achievement Award from the International Society for Autism Research



On May 1, 2025, Joseph Piven, MD, the Thomas E. Castelloe Distinguished Professor of Psychiatry at the UNC School of Medicine and director of the Carolina Institute for Developmental Disabilities (CIDD), was awarded the Lifetime Achievement Award by the International Society for Autism Research.

The award, the most prestigious honor in the field of autism research, recognizes the career of a researcher who has made significant advances to understanding autism that have made a lasting impact on the field. The Lifetime Achievement Award recipient is decided by the society's board of directors, who are prominent international autism researchers themselves.

"This distinguished honor celebrates Dr. Piven's visionary leadership and enduring contributions to autism research," stated INSAR when presenting the award. "His work has shaped the field and inspired generations of scientists and clinicians."

The International Society for Autism Research is the largest and most prominent autism research society in the world. Piven received the award at the society's international meeting, held this year in Seattle, and he gave an acceptance speech overviewing his career's work to an audience of over 2,400 international autism researchers. "I am immensely honored to receive this award from my peers in the international autism research community, many of whom I have known for over 20 years," said Piven.

Piven is a child, adolescent and adult psychiatrist at UNC School of Medicine, and he is founding director of the UNC CIDD, where he oversees its comprehensive program of research, clinical care, and specialized training in developmental disabilities. The CIDD, funded primarily through federal grants, provides multidisciplinary clinical care for newborns to adults, conducts basic to applied research and clinical trials, and has trained hundreds of clinicians and researchers.

The mission of CIDD's bench-to-bedside comprehensive approach is to help improve the lives of individuals with developmental disabilities and their families throughout North Carolina and the United States. CIDD has also received continuous funding since the 1960s to serve as a University Center for Excellence in Developmental Disabilities.

"UNC is a shining star in developmental disabilities research, training, and clinical care thanks to the visionary leadership of Dr. Piven," said Gabriel Dichter, PhD, associate director for research at the CIDD. Piven's research program has been robust, emphasizing interdisciplinary team science in MRI brain imaging, family studies, and molecular genetics, aimed at discovering the pathogenesis of autism and related neurogenetic syndromes. He is the author of over 250 peer-reviewed publications on neurodevelopmental disabilities.

Piven has served as principal investigator on several national research centers on autism, including an Autism Center of Excellence of the U.S. National Institutes of Health. UNC is the only Autism Center of Excellence in the U.S. that has been funded by NIH for the four consecutive grant cycles of this funding mechanism, generating a total of 20 years of research.

Continued on next page

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A University Center for Excellence in Developmental Disabilities (UCEDD), the CIDD is part of a network of interdisciplinary centers dedicated to advancing policy and practice for and with individuals with developmental and other disabilities and their families through education, research, and service.

The CIDD is also home to the Intellectual and Developmental Disabilities Research Center (IDDRC) at UNC, which promotes collaborations across disciplines and supports investigators conducting funded research relevant to improving understanding of neurodevelopmental conditions through the provision of a range of research cores.

As a Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program, the CIDD provides interdisciplinary training opportunities to prepare the next generation of professionals advancing developmental disability advocacy, policy, and care.

Piven Earns Prestigious Lifetime Achievement Award from the International Society for Autism Research *continued*

The UNC Autism Center of Excellence is the lead university for the Infant Brain Imaging Study (IBIS) Network, which has discovered early brain markers for autism as early as 6 months of age, before the onset of diagnostic behavioral symptoms of autism. These biomarkers are detectable by a non-invasive MRI scan at 6 months and could predict which babies went on to develop autism two years later.

Piven has also played a momentous role in inspiring the next generation of researchers. Mark Shen, PhD, an assistant professor of psychiatry and neuroscience at UNC School of Medicine and co-director of the CIDD Clinical Trials Program, was a former postdoctoral fellow mentored by Piven. "Joe's mentorship and leadership has been pivotal in helping the career development of early career researchers; in fact, dozens of his mentees are now leading their own research labs at top universities across the country," said Shen.

The CIDD also houses an Intellectual and Developmental Disabilities Research Center, one of fourteen of its kind. Supported by the National Institute of Child Health and Human Development (NICHD), the center performs studies on gene-brain-behavior relationships, early brain and behavior development, and early detection and intervention.

Jason Stein Named 2024-25 Yang Family Biomedical Scholar

The UNC School of Medicine has named three outstanding researchers as recipients of the eighth annual Yang Family Biomedical Scholars Award! They are: Jason Stein, PhD, associate professor of Genetics and member of the UNC Neuroscience Center and Carolina Institute for Developmental Disabilities; Gaorav Gupta, MD, PhD, associate professor of Radiation Oncology and member of UNC Lineberger Comprehensive Cancer Center; Misty Good, MD, MS, associate professor of Pediatrics and Chief of the Division of Neonatal-Perinatal Medicine.

Each faculty member will receive a generous grant to be used at their discretion for biomedical research projects at the UNC School of Medicine. The researchers are now members of the Yang Family Society of Biomedical Scholars, which will host its annual seminar to highlight their work later this summer. The awards were made possible through donations from Yuanqing Yang, Chairman and CEO of Lenovo, with additional financial support from Mr. To Hing Wu, an associate to Mr. Yang.

Jason Stein, PhD

With the Yang Scholars program, the UNC School of Medicine has established a community of dedicated, promising young tenured faculty. The award recognizes faculty that have made significant scholarly contributions to their field while also receiving national recognition for their research.

Dr. Stein's research explores how variations in the genome change the structure and development of the brain, and in doing so, create risk for neuropsychiatric illness. This work identified the first highly significant and replicated common variants influencing brain structure. His lab also studies genetic control of human cortical development through the identification of genetic variants that influence the expression of nearby genes.

One of the recent cutting-edge developments in the Stein lab is the establishment of cortical organoids from induced pluripotent stem cells (IPSCs) harvested from blood samples from individuals with autism and those without. These organoids are used to understand the cellular and molecular mechanisms leading to brain overgrowth in individuals with autism. The Stein lab has also successfully moved into new fields of study, evidenced by the awarding of a new Alzheimer's disease U01 grant from NIA focused on modeling gene x environment interactions using the cortical organoid model.

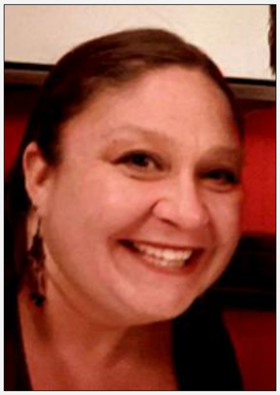
CIDD Family Support Program

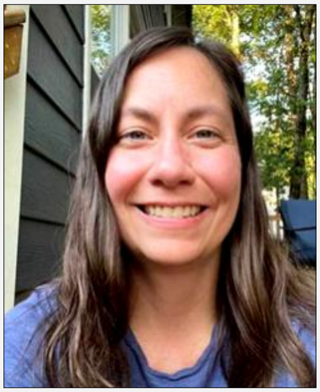
CIDD Family Support Services continues to grow under the leadership of Morgan Parlier, LCSW, Kim Schlegel, LCSWA, and Rob Christian, MD. Family Support Services at CIDD primarily functions to help NC families navigate our often-complex IDD support system. Family System Navigators are the backbone of the program. These individuals have lived experience providing support to individuals with IDD and complex needs. They have training on working with families and professionals and have specialized knowledge on how to “connect the dots” of a fragmented system. Along the way they teach and train each other, the families they serve, and the health professionals who seek their services. CIDD currently has 6 family system navigators supported by several different projects with overlapping aims. The core funding source is the NC Department of Health and Human Services, with additional support from Duke University, the Arc of North Carolina and Trillium Health Resources.

Through additional funding provided by Health Resources and Services Administration, and an enhanced collaborative partnership between UNC Department of Neurology and CIDD to focus on systems improvement for youth/young adults (ages 13-26) with a seizure disorder and co-occurring IDD, the Whole Brain Health Program will be recruiting 1-2 additional Family System Navigators in 2025.

CIDD Family Support Services is emerging as a leader in envisioning and implementing systemic approaches that promote family and patient-centered care that bridges from clinic to community. We look forward to continued capacity building in this arena, as we know that even with the acquisition of excellent clinical care through UNC, families require additional support in managing and navigating services for children and adults with IDD and co-occurring medical and/or behavioral complexity. We look forward to exploring additional partnerships and funding toward this broader goal. For additional information, please contact Morgan Parlier at morgan.parlier@cidd.unc.edu.


Morgan Parlier, Director
Family Support Services


Kim Schlegel, Associate Director
Family Support Services


Jessica Gutierrez
Family Support Coordinator
FSN


Katie Keuhner
Family System Navigator
C3Y


Hannah Russel
Family System Navigator
C3Y—Trillium


Shermekka Williams
Family System Navigator
C3Y - Trillium

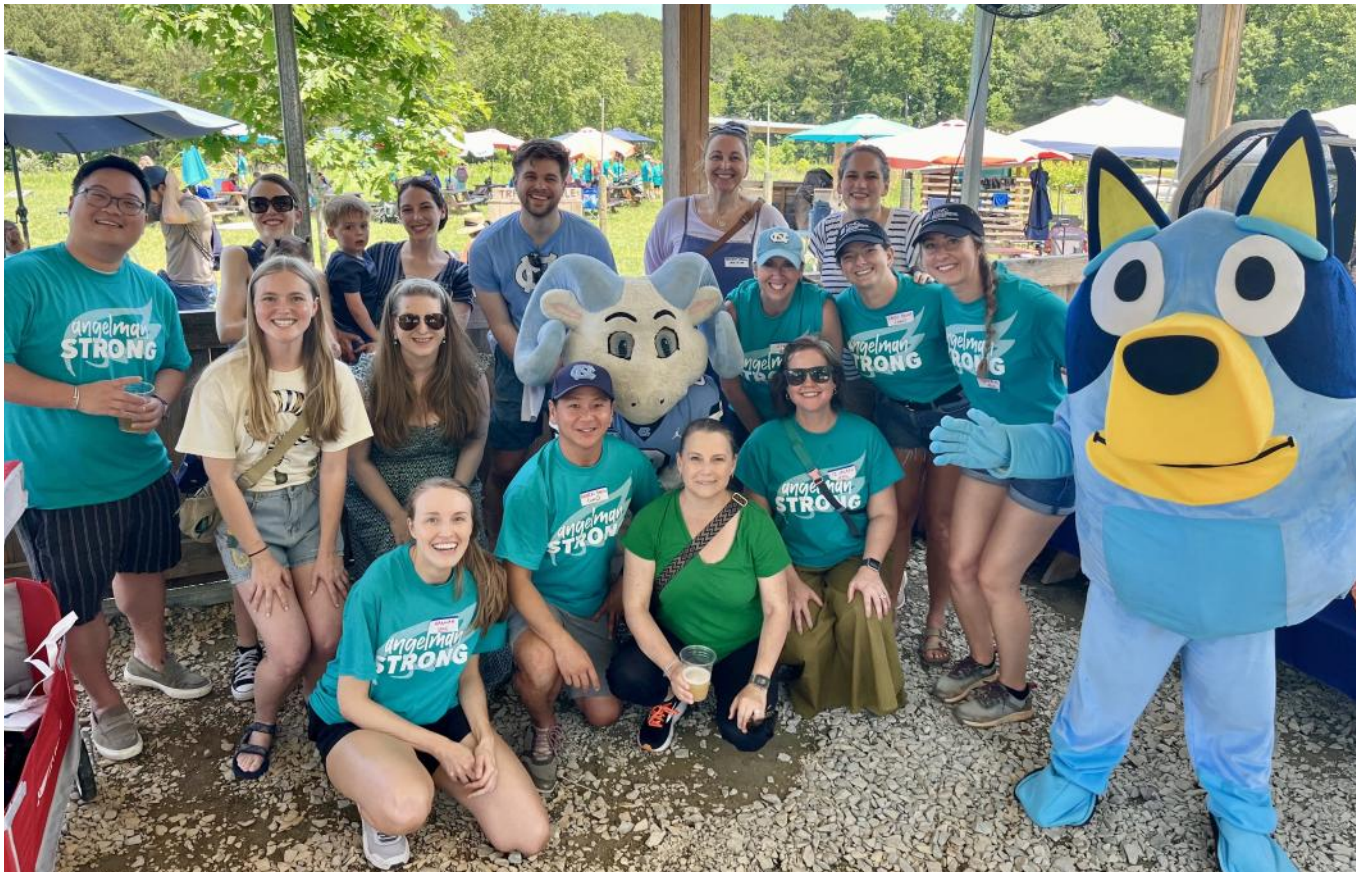

Kim Vann
Family Partner
NC PAL IDD


Joannie Olander
Family Partner
NC PAL IDD

CIDD Clinical Trials Program, Joined by 20 UNC Clinicians and Researchers, Raised over $44,000 for the Angelman Syndrome Foundation

This year, members of the CIDD Clinical Trials Program, Caisi Hecht and Cheryl Phillips, organized the first-ever Angelman Strong Community Event for North Carolina, which took place at Pluck Farm on May 17, 2025. The event brought together families with Angelman syndrome from across North Carolina, southeastern U.S., and as far away as New Jersey, many of whom have participated in CIDD's Angelman clinic, research studies, and clinical trials. The event was attended by over 150 people – from parents, individuals with Angelman syndrome, alongside UNC and CIDD researchers and clinicians – to enjoy a day in the sun with water play, music, games, food and drinks, and even guest appearances from UNC mascot Ramses Jr. and Bluey! (see picture) Many families look forward to this event every year as a way to raise awareness, fundraise for the Angelman Syndrome Foundation (ASF), and come together as a community. This year, our North Carolina community raised over $44,000 to fund critical research, clinical trials, and supportive resources for AS families.

For over 25 years, the Angelman Syndrome Foundation Walks have united and empowered the Angelman syndrome community, building an incredible network of support. The Angelman Strong event is a new initiative designed to grow and strengthen the support for our loved ones with AS. The mission remains the same: raising awareness of Angelman syndrome and essential funds for Angelman research and family support programs. This event was an inspiring and uplifting experience for everyone involved; the support for each other is tangible and serves as a reminder of why we do the work that we do. Thank you to everyone who helped fundraise over the course of this past year or showed their support!



First row from left: Hannah Riehl, Mark Shen, Jean Mankowski, Liz Jalazo. Second row: Natalie Claypool, Jennifer Mathews, Ramses Jr., Lisa Petersen, event organizers & coordinators on the CIDD Clinical Trials Program Caisi Hecht & Cheryl Phillips, and Bluey. Third row: Zumin Chen, Dea Garic, Jessica Girault, Zach Arnold, Margaret DeRamus, Mary Clay Federspiel.

Attended but not pictured: Jane Fan, Anne Wheeler, Heather Hazlett, Matt Judson's family, Stefan Lemke, Kelly Caravella, Leigh Anne Weisenfeld.

The Infant Down Syndrome Brain and Behavior Study

Heather Hazlett, PhD

The National Institutes of Health (NIH) has launched a long-term study to observe and track health data of people with Down syndrome from birth to adulthood. The initiative is led by NIH's INCLUDE program and is called the Down syndrome Collaboration for Down syndrome Progress (DS-CDP), which aims to engage and enroll thousands of individuals with Down syndrome, including those who have been historically underrepresented in Down syndrome research.

Down syndrome (DS) is the most common genetic cause of intellectual disability, yet progress has been very limited in understanding how early brain development in DS relates to long-term functional outcomes. In this project, the Infant Brain Imaging Study, a multisite, multidisciplinary team with over 15 years' experience in infant recruitment and collection of longitudinal behavioral and neuroimaging data in typically developing infants and infants with autism spectrum disorder (ASD), DS, and fragile X syndrome, will collect comprehensive, state-of-the-art brain and behavioral data in infants with DS at ages 6, 12, and 24 months, with collection at five clinical sites (including UNC-Chapel Hill) across the U.S. These data will allow identification and tracking of early brain differences in DS and their relationships to behavior, which can help guide intervention research aimed at improving developmental outcomes.

Recruitment for the study is expected to begin in the latter half of 2025, with the INCLUDE program expanding to include new study sites over the next five to ten years.

CIDD's Heather Hazlett, PhD, is co-PI of the Infant Down Syndrome Brain and Behavior Study CDP, along with Dr. Natasha Marrus from Washington University. Several other CIDD faculty are involved in the study, including Rebecca Grzadzinski, Mark Shen, Dea Garic, and Joseph Piven.

Morgan Parlier Receives Provost's 2025-26 ELEVATE Fixed-Term Faculty Development Award

Morgan Parlier, MSW, LCSW

CIDD faculty member Morgan Parlier, MSW, LCSW, has been named a 2025-26 ELEVATE Fixed-Term Faculty Development Award recipient by the UNC Office of the Provost. Ms. Parlier is among 17 faculty members across the University selected for this honor. The ELEVATE Faculty Support Program provides awards up to $25,000 to support fixed-term faculty in their research and scholarly endeavors, offering recipients flexible funding to drive innovative projects. Aimed at fostering excellence in research, scholarship, and pedagogical innovation, ELEVATE provides recognition and support to elevate the impact and success of fixed-term faculty members within the academic community.

In representation of the CIDD Sexual Health Education team, co-led by Ms. Parlier and Margaret DeRamus, MS, CCC-SLP, Ms. Parlier endeavors to dedicate a portion of her effort over the next year to Reducing Interpersonal Violence (IPV) and Promoting Sexual Health Equity in the Intellectual and Developmental Disabilities Community.

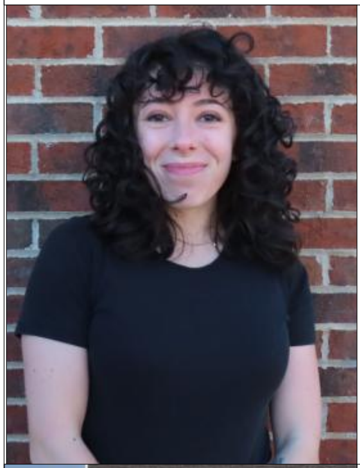
With the financial support of the ELEVATE award, Ms. Parlier will:

1. Review current literature, existing programs, and state and national target population statistics. In consultation with Ms. DeRamus, she will broaden current training and education curricula from the existing scope of Sexual Violence Prevention to Interpersonal Violence Prevention IPV in the IDD community.

2. Expand community, regional, and statewide partnerships to promote increased awareness and expansion of IDD inclusive prevention and intervention services across the state.

Sonny Russell and Clara Thörn Receive CIDD Research Award

The CIDD Research Award is offered annually to assist with defraying the costs associated with presenting or conducting research related to intellectual and developmental disabilities. This award is available to CIDD-affiliated graduate students, postdoctoral fellows, and other trainees actively engaged in intellectual and developmental disabilities research.



Alison (Sonny) Russell, a doctoral student in the Developmental Psychology program at UNC Chapel Hill, was a panelist at the International Society for Autism Research (INSAR) 2025 Annual Meeting. The panel session, Not Autism. Not Yet. Characterizing the Diagnostic Experiences and Profiles of Late, Missed and Mis-Diagnosed Individuals, included Russell's talk, Pathways to an Autism Diagnosis: Insights from Parents of Females.

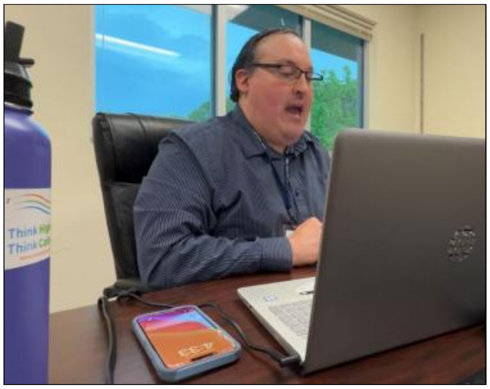
Females receive autism diagnoses significantly later than males, contributing to delayed access to supports. Person- and society-level characteristics intersect with racial/ethnic status, which can further delay access to a timely autism diagnosis. Understanding barriers to, and pathways towards, an autism diagnosis is crucial to lowering the average age of diagnosis for females, particularly those from minoritized backgrounds. The study sought to quantitatively and qualitatively characterize the diagnostic pathway from parental first concern to an autism diagnosis for autistic females.

Clara Thörn, M.Ed, BCBA, a doctoral candidate in the School Psychology program at UNC Chapel Hill, presented two posters at the National Association of School Psychologists (NASP) Annual Convention in Seattle in February 2025. One poster focused on supporting parental mental health during autism eligibility discussions, highlighting the importance of strengths-based communication, validating caregiver challenges, and fostering family-school collaboration. The second poster addressed the co-occurrence of autism spectrum disorder (ASD) and attention-deficit/hyperactivity disorder (ADHD), emphasizing the need for comprehensive assessment practices and tailored supports to address overlapping and distinct symptoms across both conditions.

Advocacy in the Disability Community

CIDD Disability Advocate and podcaster, Kenneth Kelty, calls for more disability support in the North Carolina budget.

The NC waitlist for Innovations Waivers has almost 19,000 people on it, and it's growing. Governor Josh Stein is pushing for more funding for waiver spots in the budget, which pay for people to give direct support to people with intellectual and developmental disabilities. Even with waivers, many people living with intellectual or developmental disabilities can't find direct support.

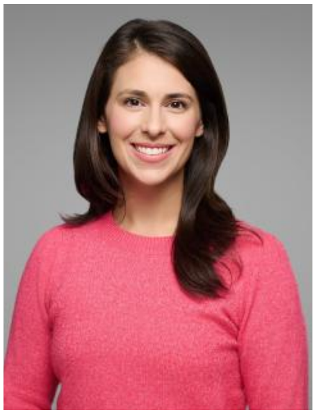


Kenneth Kelty records a podcast episode. (Spectrum News 1/Marshall Keely)

CIDD's employee and disability advocate, Kenneth Kelty, waited on the Innovations Waivers list for 14 years before he got a slot in the program. "I am a pretty independent person, but I still need help with being able to pay bills, and I still would like to be able to have someone take me out in the community," he said. Kelty's waiver means he lives in a rent-controlled apartment and has help getting around, offering him freedoms he'd otherwise lose.

"If I did not have a DSP come or the waiver, I might unfortunately be stuck at home or a more segregated placement," Kelty said. But he's still talking to many in his community who haven't yet been afforded the same opportunities. "They're missing out on meaningful experiences," he said. His ask to lawmakers, for himself and for the people he's meeting, is simple. "I just want to be able to live my life and not have to worry about getting services or what could happen if I don't," Kelty said. Read full article in Spectrum News.

Improving Developmental Outcomes for Rural Toddlers Through Family Navigation



Kelly Caravella, PhD

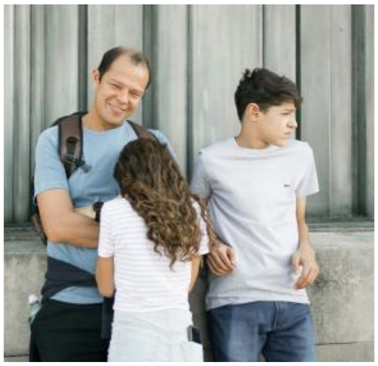
Kelly Caravella, PhD, has been awarded a grant from the Foundation of Hope for Research and Treatment of Mental Illness.

Early diagnosis of autism is important, however, it must be followed by starting autism-specific treatments quickly to help children meet their developmental goals. Unfortunately, many families, especially those in rural areas, face long delays in getting these treatments due to a lack of specialists, travel difficulties, and less awareness about autism service availability.

Family Navigation has been shown to help reduce the time to get an autism diagnosis by providing a knowledgeable support person to guide families through complex healthcare systems. This study will investigate whether Family Navigation, delivered through telehealth, can expedite access to autism-specific treatment for rural toddlers, aiming to improve developmental outcomes and gather preliminary data for a larger program to improve access to autism treatments for young children in rural North Carolina.

Local Fathers' Group Expanding Its Reach

For the past 5 years, a virtual support group for fathers of autistic individuals has been sponsored by the Carolina Institute for Developmental Disabilities and UNC TEACCH. Initially created by Dr. Joe Piven and currently co-facilitated by Dr. Gabriel Dichter and Mr. Daniel Liles, this support group was created to provide a forum for fathers to discuss issues related to parenting autistic individuals, including family dynamics, acceptance, self-care, coping mechanisms, and sharing resources.



This fathers' group was an outgrowth of the first UNC Autism Fathers Conference in 2019, developed by Dr. Piven to shine a spotlight on the unique needs of fathers of autistic individuals. Piven organized the virtual support group to talk about challenges fathers face raising an autistic child. A common theme of the group, which is typically attended by 10-15 fathers, is that whereas each family is unique, many challenges are shared across families. These include strategies to find the best medical and psychiatric care, locating social opportunities, and identifying resources to help navigate the educational system using IEPs or requesting accommodations. Another common theme is that fathers of autistic individuals are in a unique situation best understood by others in similar circumstances.

The group also provides an opportunity for fathers to form connections among themselves through informal in-person gatherings: last year the group organized a bowling night with food, drinks and lots of laughs. "We had a great time getting to know one another on a more personal level," one father noted. "We look forward to building out the group with new fathers who are seeking both knowledge and commonality with others in a similar position." The group meets every six weeks from 6:30-8pm EST via Zoom. If you are interested in joining, please contact Gabriel Dichter at dichter@med.unc.edu or Daniel Liles at daniel_liles@med.unc.edu.

SUPPORT THE CAROLINA INSTITUTE FOR DEVELOPMENTAL DISABILITIES

The programs of the Carolina Institute for Developmental Disabilities provide innovative, high-quality clinical, research, and training activities supporting individuals with developmental disabilities. Now, more than ever, we need well-trained practitioners, teachers, and researchers. State funds pay only part of the costs to recruit and retain the best faculty and support the unique training and programs that are the hallmarks of the CIDD experience. It is private funds that sustain and enhance these extraordinary opportunities for students, patients, families, and faculty. We can't do it without you! A gift to the Carolina Institute for Developmental Disabilities is an investment in the lives of thousands and in the future of our communities. Join us by giving today. To make a donation by credit card, please visit the UNC Health Foundation gifting page and choose "Carolina Institute for Developmental Disabilities:" Click Here. Email info@cidd.unc.edu or call 919-966-5171 for more information about supporting the CIDD.