



Inside the Institute

Issue # 30
October 2021

LEND Program at UNC-CH Awarded \$3.5 Million for Leadership Education in Neurodevelopmental and Other Related Disabilities (LEND)

The NC Leadership Education in Neurodevelopmental and Other Related Disabilities (LEND) program, based at the Carolina Institute for Developmental Disabilities in the UNC School of Medicine, has successfully competed for continuation of its decades long funding by the U.S. Maternal and Child Health Bureau (MCHB) within the Health Resources and Services Administration (HRSA). Awards were announced in June 2021 for 60 programs, located at universities and children’s hospitals across the nation, for the 2021-2026 funding cycle. LEND is one of several initiatives funded by federal Autism CARES legislation.

The purpose of LEND programs is to improve the health of individuals who have, or are at risk for developing, autism spectrum disorder and other developmental disabilities by providing graduate-level training in maternal and child health interdisciplinary leadership education.

LEND provides interdisciplinary opportunities for trainees to access content and experiences beyond the scope of their academic disciplines to increase the capacity of the workforce prepared to meet the complex needs of individuals with ASD/DD. LEND activities include a robust interdisciplinary educational curriculum, clinical service, research, technical assistance, and continuing education. Trainees are engaged at varying levels of intensity through long-, medium-, and short-term training opportunities; specific emphasis is on engaging diverse cohorts of trainees and faculty, including those from underrepresented racial and ethnic groups, geographic regions, and other factors reflecting the broader population. NC-LEND is committed to training a minimum of 30 long-term trainees per year (300+ hours) consisting of graduate level interdisciplinary trainees, family members, and self-advocates dedicated to working with and improving the system of care for individuals with ASD/DD.

Dr. Becky Pretzel, NC-LEND Director, notes, “The North Carolina LEND Program has maintained consistent funding and offered important leadership education in developmental disabilities for many years, thus building much needed capacity within our state. Renewal of our LEND grant will enable us to continue our work for another five years along with our partners at UNC-Greensboro, Duke, North Carolina Central University, North Carolina State University, as well as state agencies including the Department of Health and Human Services and the Department of Public Instruction.”



Becky Pretzel, PhD



Rob Christian, MD



Jean Mankowski, PhD

The NC-LEND program is led by Dr. Becky Pretzel, Director; Dr. Rob Christian, Associate Director; and Dr. Jean Mankowski, Training Director. The program is strengthened by the strong teaching and mentorship of multiple faculty members within the CIDC and other UNC-Chapel Hill centers and departments.

IN THIS ISSUE

| | |
|---------------------------------|----|
| NC-LEND Audiology Grant | 2 |
| DEI Town Hall | 2 |
| New Neurodevelopmental Syndrome | 3 |
| Community Collaboration | 4 |
| microRNA-29 Abnormalities | 5 |
| AIR-P Scholars Awards | 6 |
| Parent Responsiveness | 6 |
| 2021 T32 Postdoctoral Trainees | 7 |
| Young Investigator Award | 8 |
| NC-LEND Trainee Scholarships | 8 |
| Hyejung Won Lab | 9 |
| Itano Editor of BioTechniques | 10 |
| Best Practices and Tools | 10 |
| Piven Appointed to IACC | 11 |
| Angelman Syndrome Experts | 11 |
| Think College Policy Advocates | 12 |
| HEELS 2 Transition | 12 |
| NC-LEND 2021-22 Trainees | 13 |
| AUCD “Emerging Leader” | 15 |
| “Let’s Talk” Group | 15 |
| Community Talk Series | 16 |
| COVID 19 Vaccination Efforts | 16 |
| Free Rides to Vaccination Sites | 17 |
| Your Support | 17 |



Jackson Roush, PhD

NC-LEND Awarded Pediatric Audiology Supplemental Grant

On page 1 of *Inside the Institute* we shared good news from the U.S. Maternal and Child Health Bureau and Health Resources and Services Administration (HRSA) that the North Carolina LEND Program will be awarded \$3.5 million for the 2021-2026 cycle. This made us eligible to apply for a Pediatric Audiology Competitive Supplement to NC-LEND with funding from HRSA to prepare pediatric audiologists to work with children who are deaf or hard of hearing with autism and other developmental disabilities. We are pleased to report that the NC-LEND program at CIDD has again competed successfully for this grant and will receive an additional \$375,000 over the next five years to continue this specialized training.



Hannah Siburt, AuD, PhD

CIDD audiologist and LEND faculty member, Dr. Jackson Roush, notes, "We were proud to receive one of the first three LEND audiology supplemental grants when they were first awarded in 2009 and are very pleased to receive continuation of this funding through 2026, to prepare pediatric audiologists from UNC's Doctor of Audiology (AuD) program with the knowledge and skills needed to work with children and families when hearing loss occurs with developmental disabilities or other complex needs." Leading the supplemental grant with Dr. Roush is Dr. Hannah Siburt, an audiologist on the faculty in the Division of Speech and Hearing Sciences at UNC who joined the CIDD/LEND faculty earlier this year.

Proposals for the supplement were submitted from LEND programs across the U.S. and 12 were selected for supplemental funding. Further details are available at <https://www.hrsa.gov/grants/find-funding/hrsa-21-042>

CIDD hosts the Inaugural Diversity, Equity, and Inclusion Town Hall



Brenda Mitchell, PhD

On September 29, 2021, the CIDD hosted our first Diversity, Equity, and Inclusion (DEI) Town Hall, "Diversity, Equity, and Inclusion: What's the Point?" The event, which took place via ZOOM, was facilitated by Dr. Brenda Mitchell, Chair of the UNC Department of Allied Health Sciences Diversity and Inclusion Leadership Team; UNC School of Medicine Diversity and Inclusion Committee. Dr. Mitchell is also the Associate Chair of the Department of Allied Health Sciences Office of Student Services and AHEC.

Dr. Mitchell has a wealth of experience in DEI leadership and training and lead the nearly 50 CIDD faculty, staff, and trainees who attended the town hall in an informative discussion.

CIDD DEI Committee Co-Chairs, Diana Cejas, MD, MPH, and Morgan Parlier, MSW, LCSW, presented information about the DEI committee, our diversity and solidarity statements, and plans for DEI activities at CIDD. In breakout groups attendees also discussed the concepts of feeling othered and being welcomed. At the conclusion of the town hall, all were invited to join in on the CIDD's monthly DEI meetings. The next meeting will be held on October 22, 2021 at 3:00 PM.



Diana Cejas, MD, MPH



Morgan Parlier, MSW, LCSW

Scientists Find Genetic Cause, Underlying Mechanisms of New Neurodevelopmental Syndrome



Damaris Lorenzo, PhD

Scientists at the University of North Carolina at Chapel Hill School of Medicine and colleagues have demonstrated that variants in the SPTBN₁ gene can alter neuronal architecture, dramatically affecting their function and leading to a rare, newly defined neurodevelopmental syndrome in children.

Damaris Lorenzo, PhD, assistant professor in the UNC Department of Cell Biology and member of the UNC Neuroscience Center and Intellectual and Developmental Disabilities Research Center (IDDRC) within the Carolina Institute for Developmental Disabilities, led this research, which was published in the journal *Nature Genetics*.

The gene SPTBN₁ instructs neurons and other cell types how to make β II-spectrin, a protein with multiple functions in the nervous system. Children carrying these variants can suffer from speech and motor delays, as well as intellectual disability. Some patients have received additional diagnosis, such as autism spectrum disorder, ADHD, and epilepsy. Identification of the genetic variants that cause this broad spectrum of disabilities is the first important milestone to finding treatments for this syndrome.

Lorenzo first learned about patients with complex neurodevelopmental presentations carrying SPTBN₁ variants from Queenie Tan, MD, PhD, a medical geneticist, and Becky Spillmann, MS, a genetic counselor – both members of the NIH-funded Undiagnosed Disease Network (UDN) site at Duke University and co-authors of the *Nature Genetics* paper. They connected with Margot Cousin, PhD, a geneticist associated with the UDN site at the Mayo Clinic and co-first author of the study. Cousin had also collected clinical information from SPTBN₁ variant carriers. Other clinical genetics teams learned about these efforts and joined the study.

The cohort of individuals affected by SPTBN₁ variants continues to grow. Lorenzo and colleagues have been contacted about new cases after they published a preprint of their initial findings last summer. Identifying the genetic cause of rare diseases such as the SPTBN₁ syndrome requires pooling knowledge from several patients to establish common clinical and biological patterns.

“Fortunately, the advent of affordable gene sequencing technology, together with the creation of databases and networks to facilitate the sharing of information among clinicians and investigators, has vastly accelerated the diagnosis of rare diseases,” Lorenzo said. “To put our case in historical perspective, β II-spectrin was co-discovered 40 years ago through pioneering work that involved my UNC colleagues Keith Burridge, PhD, and Richard Cheney, PhD, as well as my postdoctoral mentor Vann Bennett, PhD, at Duke. However, its association with disease eluded us until now.”

β II-spectrin is tightly associated with the neuronal cytoskeleton – a complex network of filamentous proteins that spans the neuron and plays pivotal roles in their growth, shape, and plasticity. β II-spectrin forms an extended scaffolding network that provides mechanical integrity to membranes and helps to orchestrate the correct positioning of molecular complexes throughout the neuron. Through research published in *PNAS* in 2019, Lorenzo found that β II-spectrin is essential for normal brain wiring in mice and for proper transport of organelles and vesicles in axons – the long extensions that carry signals from neurons to other neurons. β II-spectrin is an integral part of the process that enables normal development, maintenance, and function of neurons.

In this new study, Lorenzo’s research team showed that, at the biochemical level, the genetic variants identified in patients are sufficient to cause protein aggregation, aberrant association of β II-spectrin with the cytoskeleton, impair axonal organelle transport and growth, and change the morphology of neurons. These deficiencies can permanently alter how neurons connect and communicate with each other, which is thought to contribute to the etiology of neurodevelopmental disorders. The team showed that reduction of β II-spectrin levels only in neurons disrupts structural connectivity between cortical areas in mutant mice, a deficit also observed in brain MRIs of some patients.

In collaboration with Sheryl Moy, PhD, professor in the UNC Department of Psychiatry and director of the Mouse Behavioral Phenotyping (MBP) Core of the UNC IDDRC, the researchers found that these mice have developmental and behavioral deficits consistent with presentations observed in humans.

“Now that we’ve established the methods to assign likelihood of pathogenicity to SPTBN₁ variants and to determine how they alter neurons, our immediate goal is to learn more about the affected molecular and cellular mechanisms and brain circuits, and evaluate strategies for potential clinical interventions,” Lorenzo said.

Continued on next page

North Carolina Community Collaboration for Employment



Brianne Tomaszewski, PhD

Dr. Brianne Tomaszewski is the Principle Investigator of the North Carolina Community Collaboration for Employment funded by the United States Department of Health and Human Services Administration for Community Living Developmental Disabilities Projects of National Significance. The team is interdisciplinary and includes individuals from the Department of Psychiatry, TEACCH, CIDD, Department of Allied Health, School of Education, School of Social Work, Frank Porter Graham Child Development Institute, and critical community collaborators from NC DHHS, including Vocational Rehabilitation, Department of Public Instruction, and other organizations providing transition and employment services for individuals with ID/DD.

Anna Ward, Director of Advocacy and Inclusion at the CIDD, will serve as the Project Director. LEND Self Advocacy Faculty, McCafferty S. Kermon will serve as consultant.



Anna Ward

McCafferty S. Kermon

Over the next five years, the \$1.1 million grant will optimize opportunities for competitive integrated employment, postsecondary education, and independent living for individuals with ID/DD and their families in the Triangle and Triad regions of NC. This project aims to increase the capacity of the Triangle and Triad regions in NC to provide, expand, and strengthen transition services and facilitate improved transition activities between schools and their local organizations for individuals with ID/DD. The objectives are to:

1) establish an NC Community Employment Collaborative with state and regional participants, 2) conduct a landscape analysis, 3) develop a Community Collaboration Employment Transition Plan, and 4) implement the Community Collaboration Employment Transition plan. The long-term goal will be to sustain the NC Community Employment Collaboration and extend it to a statewide system.

Scientists Find Genetic Cause, Underlying Mechanisms of New Neurodevelopmental Syndrome *continued*

To this end, her team will collaborate with Adriana Beltran, PhD, assistant professor in the UNC Department of Genetics and director of the UNC Human Pluripotent Cell Core, to use neurons differentiated from patient-derived induced pluripotent stem cells. And the research team will continue to tap into molecular modeling predictions in collaboration with Brenda Temple, PhD, professor in the UNC Department of Biochemistry and Biophysics and director of the UNC Structural Bioinformatics Core, both co-authors on the Nature Genetics paper.

"As a basic science investigator, it's so satisfying to use knowledge and tools to provide answers to patients," Lorenzo said. "I first witnessed this thrill of scientific discovery and collaborative work as a graduate student 15 years ago when our lab identified the genetic cause of the first spectrinopathy affecting the nervous system, and it has been a powerful motivator since." That work was the discovery of variants in a different spectrin gene as the cause of spinocebellar ataxia type 5 (SCA5), led by Laura Ranum, PhD, who at the time was at the University of Minnesota. In follow up work, as part of that team, Lorenzo contributed insights into the pathogenic mechanism of SCA5.

"Aside from the immediate relevance to affected patients, insights from our work on SPTNB1 syndrome will inform discoveries in other complex disorders with overlapping pathologies," Lorenzo said. "It is exciting to be part of such important work with a team of dedicated scientists and clinicians."

Members of the Lorenzo lab who are co-authors in the Nature Genetics paper are co-first author Blake Creighton, lab research technician in the Lorenzo lab; Reggie Edwards, graduate student; Keith Breau, graduate student at the time of this research; Deepa Ajit, PhD, a postdoctoral fellow; Sruthi Dontu, Simone Afriyie, and Julia Bay, all undergraduates at UNC-Chapel Hill; and Liset Falcon, lab research technician at the time of this research. Other UNC-Chapel Hill collaborators and co-authors in the paper are Kathryn Harper, PhD, project manager in the MBP Core; and Lorena Munoz and Alvaro Beltran, both research associates in the hHPSC. This research was funded by grants from the National Institutes of Health and the National Ataxia Foundation.

Key Brain Molecule May Play Role in Many Brain Disorders



Mohanish Deshmukh, PhD

A team led by scientists at the UNC School of Medicine identified a molecule called microRNA-29 as a powerful controller of brain maturation in mammals. Deleting microRNA-29 in mice caused problems very similar to those seen in autism, epilepsy, and other neurodevelopmental conditions. The results, published in [Cell Reports](#), illuminate an important process in the normal maturation of the brain and point to the possibility that disrupting this process could contribute to multiple human brain diseases.

"We think abnormalities in microRNA-29 activity are likely to be a common theme in neurodevelopmental disorders and even in ordinary behavioral differences in individuals," said senior author Mohanish Deshmukh, PhD, professor in the UNC Department of Cell Biology & Physiology and member of the UNC Neuroscience Center and the UNC Intellectual and Developmental Disabilities Research Center (IDDRC). "Our work suggests that boosting levels of miR-29, perhaps even by delivering it directly, could lead to a therapeutic strategy for neurodevelopmental disorders such as autism."

miR-29 and brain maturation

MicroRNAs are short stretches of ribonucleic acid inside cells that regulate gene expression. Each microRNA, or miR, can bind directly to an RNA transcript from certain other genes, preventing it from being translated into a protein. MiRNAs thus effectively serve as inhibitors of gene activity, and the typical microRNA regulates multiple genes in this way so that genetic information is not overexpressed. These essential regulators have been intensively researched only in the past two decades. Therefore, much remains to be discovered about their roles in health and disease.

Deshmukh and colleagues set out to find microRNAs involved in the maturation of the brain after birth, a phase that in humans includes approximately the first 20 years of life. When the scientists looked for microRNAs with more activity in the adult mouse brain than the young mouse brain, one set of miRNA stuck way out from the rest. Levels of the miR-29 family were 50 to 70 times higher in the adult mouse brains than in young mouse brains.

The researchers examined a mouse model in which the genes for the miR-29 family were deleted just in the brain. They observed that although the mice were born normally, they soon developed a mix of problems, including repetitive behaviors, hyperactivity, and other abnormalities typically seen in mouse models of autism and other neurodevelopmental disorders. Many developed severe epileptic seizures. To get a sense of what caused these abnormalities, the researchers examined gene activity in the brains of the mice, comparing it to activity in mouse brains that had miR-29. As expected, many genes were much more active when miR-29 was no longer there to block their activity. But the scientists unexpectedly found a large set of genes – associated with brain cells – that were less active in miR-29's absence.

A mysterious methylator

With key assistance from co-author Michael Greenberg, PhD, a professor of neuroscience at Harvard University, the researchers eventually found the explanation for this mysterious reduction in gene activity. One of the target genes that miR-29 normally blocks is a gene that encodes for an enzyme called DNMT3A. This enzyme places special chemical modifications called CH-methylations onto DNA, to silence genes in the vicinity. In mice brains, the activity of the gene for DNMT3A normally rises at birth and then sharply declines several weeks later. The scientists found that miR-29, which blocks DNMT3A, is what normally forces this sharp decline.

Thus, in the mice whose brains lack miR-29, DNMT3A is not suppressed and the CH-methylation process continues abnormally – and many brain cell genes that should become active continue to be suppressed instead. Some of these genes, and the gene for DNMT3A itself, have been found to be missing or mutated in individuals with neurodevelopmental disorders such as autism, epilepsy, and schizophrenia. To confirm DNMT3A's role, the scientists created a unique mouse model that prevents miR-29 from suppressing DNMT3A, but leaves miR-29's other targets untouched. They showed that this unleashing of DNMT3A on its own results in many of the same problems such as seizures and early death, as seen in the mice without miR-29.

Continued on next page



Right, miRNA29-deficient mice showing a marked increase in the important enzyme DNMT3A (bright light blue). Credit: Deshmukh Lab

Jessica Kinard and Diana Cejas Receive Autism Intervention Research Network on Physical Health (AIR-P) Scholars Awards



Jessica Kinard, PhD

Diana Cejas, MD, MPH

Congratulations to Jessica Kinard, PhD, and Diana Cejas, MD, MPH, awardees in the Autism Intervention Research Network on Physical Health (AIR-P) inaugural Research Scholars program. The goal of the AIR-P Scholars program is to launch the next generation of researchers seeking to promote the health and well-being of autistic individuals across the lifespan. Dr. Kinard was selected for her project, "Evaluating a Remote Developmental Assessment for Latinx Infants and Toddlers at High Likelihood for Developing Autism." Dr. Cejas was awarded for "Patient, Parent, and Provider Partnerships in Healthcare Transition: A New Program for Youth with Autism Spectrum Disorders."

AIR-P aims to support innovative life course intervention research that promotes optimal health and well-being of autistic individuals across the lifespan. The AIR-P establishes and maintains an interdisciplinary, multicenter research network for scientific collaboration and infrastructure to increase the life expectancy and quality of life for autistic individuals, particularly for underserved and vulnerable populations. UNC's Carolina Institute for Developmental Disabilities (CIDD) is one of fifteen collaborating sites. Dr. Gabriel Dichter is PI of the CIDD site for the AIR-P Network.

Parent Responsiveness Mediates the Association Between Hyporeactivity at Age 1 Year and Communication at Age 2 Years in Children at Elevated Likelihood of ASD



Rebecca Grzadzinski, PhD

Toddlers at elevated likelihood of autism spectrum disorder (ASD) are often under-reactive (hyporeactive) to sensory stimuli. This hyporeactivity slows learning of communication skills and provides parents with fewer opportunities to respond to their children. Rebecca Grzadzinski, PhD, is an Assistant Professor in the Department of Psychiatry and member of the Carolina Institute for Developmental Disabilities. Her research examines the behavioral precursors to an autism spectrum disorder (ASD) diagnosis, changes in behaviors over time (e.g., treatment response), and the impact of child and family characteristics on child outcomes. A major focus of her work is to develop novel early interventions for infants at toddlers at risk for neurodevelopmental disorders by understanding how child, family, and dyadic (e.g., parent-child) characteristics lead to varying outcomes. Grzadzinski is lead author of [the study](#), Parent responsiveness mediates the association between hyporeactivity at age 1 year and communication at age 2 years in children at elevated likelihood of ASD, published in *Autism Research*. In this study, children with hyporeactivity at 14 months generally had poorer communication at 23 months; however, the more responsive their

parents were, the weaker the relationship between early hyporeactivity and later communication. Thus, increasing parent responsiveness may lead to better communication outcomes for toddlers with the early ASD symptom of hyporeactivity.

This research was highlighted in a summer (July 12, 2021) Autism Science Foundation (ASF) podcast. [Listen to the podcast.](#)

Key Brain Molecule May Play Role in Many Brain Disorders *continued*

The findings highlight and clarify what seems likely to be a crucial process in shaping the brain late in its development: the switching-off of DNMT3A to free up many genes that are meant to be more active in the adult brain. These results are the first to identify miR-29 as an essential regulator of CH methylation, and to show why restricting CH methylation to a critical period is important for normal brain maturation," Deshmukh said. Deshmukh and colleagues are now following up by studying in more detail how the lack of miR-29 in different sets of brain cells might give rise to such disorders, and more generally they are studying how miR-29's activity is regulated in childhood to fine-tune brain functions, thereby giving humans the traits that make them unique individuals.

The Cell Reports paper was co-first authored by Vijay Swahari, Ayumi Nakamura, and Emilie Hollville. Other authors include Hume Stroud, Jeremy Simon, Travis Ptacek, Matthew Beck, Cornelius Flowers, Jiami Guo, Charlotte Plestant, Jie Liang, Lisa Kurtz, Matt Kanke, Scott Hammond, You-Wen He, E.S. Anton, Praveen Sethupathy, Sheryl Moy, and Michael Greenberg. The research was supported by the National Institutes of Health and the Damon Runyon Cancer Research Foundation.

Announcing 2021 T32 Postdoctoral Trainees in Neurodevelopmental Disorders

The CIDD welcomes Drs. Dewran Kocak, Tehila Nugiel, and Catheryn Wilson as our incoming T32 postdoctoral trainees. The CIDD T32 Postgraduate Research Training Program develops researchers with expertise in both the biological basis and clinical manifestations of neurodevelopmental disorders. This broad-based and integrated perspective enables researchers to better relate across disciplines and maximizes the potential for major research advances in understanding the pathogenesis and treatment of these disorders. We are thrilled to have these talented postdoctoral fellows join our interdisciplinary program in neurodevelopmental disorders and would like to welcome them and introduce them to the community.



Dr. Dewran Kocak completed his PhD in Biomedical Engineering in the Gersbach laboratory at Duke University. During his graduate work he developed methods for increasing the specificity of genome-engineering. He is currently a postdoctoral associate in the Roth laboratory at UNC's Department of Pharmacology, where he is developing genome-engineering methods for the correction of Angelman Syndrome.



Dr. Tehila Nugiel received her doctorate in Psychology from the University of Texas at Austin working with Dr. Jessica Church. Her research examines brain systems supporting cognitive control in children with developmental disorders, such as learning disorders and ADHD. As a T32 Fellow at the CIDD, Dr. Nugiel will work with Dr. Jessica Cohen to examine large-scale brain systems involved in cognitive control and reward processing in ADHD, with a focus on how stimulant medication changes these systems. The ultimate goal of this program of research is to inform the development of individualized treatments targeted to dysfunctional brain systems.



Dr. Catheryn Wilson completed her PhD at the University of Arkansas for Medical Sciences (UAMS), where she studied the convulsant and cannabimimetic effects of drugs of abuse, known as synthetic cannabinoid receptor agonists, using preclinical models. At UNC-Chapel Hill, she will work in the lab of Scott Parnell, PhD, to investigate the neurobiological underpinnings of prenatal alcohol exposure-related seizure susceptibility in mice. In addition, she hopes to examine the potential role of the endogenous cannabinoid system in relation to such seizures.

Justin Wolter Earns Young Investigator Award



Justin Wolter, PhD, a T32 postdoctoral researcher currently working in the labs of Jason Stein, PhD, and Mark Zylka, PhD, at the UNC Neuroscience Research Center, the UNC Department of Genetics, and the UNC Department of Cell Biology and Physiology, was named a recipient of the 2021 Young Investigator Award by the Brain & Behavior Research Foundation (BBRF).

In his research at the UNC School of Medicine, Wolter aims to understand the molecular and cellular mechanisms of neurodevelopmental diseases. With the BBRF award, he will establish a resource to systematically identify genetic interactions between high-risk autism genes and common genetic variation. This project will build upon work in which Wolter established a cell culture-based approach to conduct genome wide association studies in primary human neural progenitor cells. Wolter will establish a pilot library of genetically diverse induced pluripotent stem cell (iPSC) lines to explore how common and rare genetic variation interact to influence risk and resilience in a genetically defined subtype of autism.

In 2020, Wolter was first author of a Nature paper from the Zylka lab showing how to use the gene-editing technology CRISPR-Cas9 as part of a potential gene therapy approach to treating Angelman syndrome, an autism spectrum disorder.

Initiated in 1987, the BBRF Young Investigator Grant program provides support for the most promising young scientists conducting neurobiological and psychiatric research. This program facilitates innovative research through support of early-career basic, translational and clinical investigators. This year, the Foundation's Scientific Council, led by Herbert Pardes, MD, and comprised of 176 world-renowned scientists with expertise in every area of brain research, reviewed more than 780 applications and selected the 150 meritorious research projects. Many of the Young Investigator grantees are pursuing basic research projects. Others are specifically focusing on new ideas for therapies, diagnostic tools, and technologies. These research projects will provide future insights and advances that will help move the fields of psychiatry and neuroscience forward.

NC-LEND Audiology Trainees Win National Scholarships



Meredith Braza, NC-LEND audiology trainee and current fourth year extern at Boston Children's Hospital, has been awarded the prestigious *Jerry Northern Scholarship in Pediatric Audiology*, given by the American Academy of Audiology Foundation to "students who show exceptional promise as clinical audiologists with a focus on the specialty of pediatric audiology." Originally from Wisconsin, Meredith completed her Bachelor's degree in Communication Sciences and Disorders at the University of Wisconsin – Madison. She will graduate from UNC with her Doctor of Audiology (AuD) degree in May, 2022. Reflecting on her LEND experience, Meredith notes: "The highlight of my graduate school experience has undoubtedly been the training I received through the LEND program. The mentorship, interdisciplinary coursework, research opportunities, and clinical experiences through LEND have prepared me to be not only a culturally sensitive, family-centered provider for children with special healthcare needs, but also an emerging leader in the field. My career goal, fueled by this LEND experience, is to serve as an educator of future professionals and an advocate for greater public health initiatives related to the hearing healthcare of children with developmental disabilities."



Shannon Culbertson, NC-LEND audiology trainee and third-year graduate student in UNC's Doctor of Audiology (AuD) program, has been awarded a national *Sertoma Communicative Disorders Scholarship for Deaf and Hard of Hearing Students* earning a graduate degree in audiology or speech-language pathology. Originally from Fresno, CA, Shannon is a graduate of California State University - Fresno where she earned a Bachelor's degree in Communicative Sciences and Deaf Studies. She is on track to graduate from UNC with her Doctor of Audiology (AuD) degree in May, 2023. Hard of hearing from birth, Shannon wants to become an audiologist to better serve the Deaf and hard of hearing community. As a board member for *Ear Community*, a resource for families affected by microtia and atresia, she uses her own experiences to advocate for others. Reflecting on her LEND experience, Shannon notes: "LEND has given me the knowledge and tools to effectively serve not only my future patients with hearing loss, but those with all abilities and disabilities."

Neuronal and Glial 3D Chromatin Architecture Informs the Cellular Etiology of Brain Disorders

Hyejung Won, PhD, Assistant Professor of Genetics, and member of the UNC Neuroscience Center and the Carolina Institute for Developmental Disabilities, is co-first author of 'Neuronal and glial 3D chromatin architecture informs the cellular etiology of brain disorders' published in Nature Communications.

"Cellular heterogeneity poses significant challenges for unraveling the complexity in the gene regulatory architecture of the human brain," noted Won. "In this work, we characterized gene regulatory networks of two major cell classes in the human brain, neurons and glia, by integrating genome-wide chromosome conformation with transcriptomic and enhancer profiles. Because brain disorders exhibit cell-type specific vulnerability, we employed cell-type specific regulatory networks to decipher cellular etiology of brain disorders."

Won and her team (pictured below) first deconvolved epigenetic dysregulation in Alzheimer's disease (AD) into the corresponding cell types. AD-associated hyperacetylation was mapped to glial enhancers that physically interact with astrocytic genes. This is in contrast to microglial enrichment of genetic risk factors for AD, suggesting that different types of glia may contribute to the disease via different regulatory mechanisms.

In addition, the team built neuronal subtype specific regulatory networks to discern discrete molecular neuropathology of two genetically shared psychiatric disorders, bipolar disorder (BD) and schizophrenia (SZ). They detected distinct cellular substrates that may contribute to the phenotypic difference between BD and SZ (BD was associated with upper layer neurons, while SZ was associated with deeper layer projection neurons), a distinction that has not been previously recognized.



Dr. Michelle Itano Named Editor-in-Chief of BioTechniques



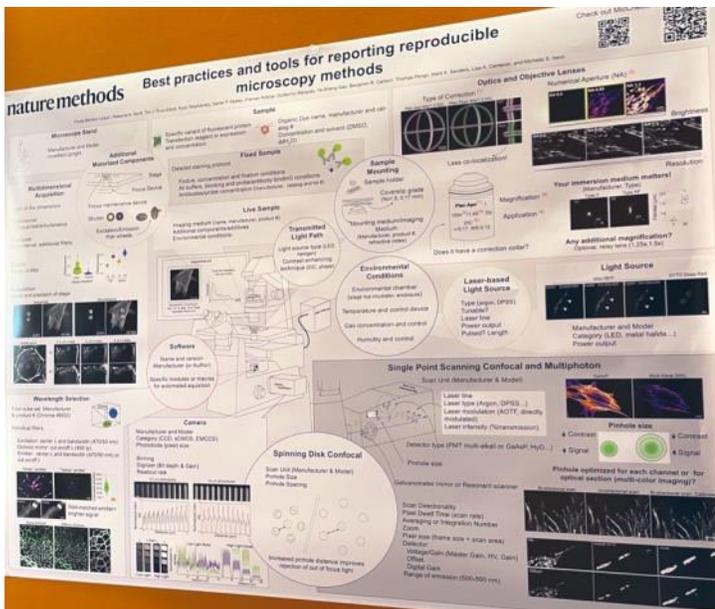
Michelle Itano, PhD, assistant professor in the UNC Department of Cell Biology and Physiology, member of the CIDD, and Director of the Neuroscience Microscopy Core in the Intellectual and Developmental Disabilities Research Center (IDDRC), was recently selected as the new editor-in-chief of BioTechniques, the International Journal of Life Science Methods. Itano joined the BioTechniques editorial board in 2020 and has made invaluable contributions to the journal since. Her new position as editor-in-chief begins immediately.

Itano develops and customizes state-of-the-art optical imaging and analysis applications for a wide range of scientific research. She uses innovative fluorescence microscopy methods, including super-resolution and simultaneous multi-plane imaging, to investigate how viruses, such as HIV-1, infect cells. In 2019, Dr. Itano was selected to be a CZI Imaging Scientist. She is also very invested in facilitating collaborations between researchers, software and infrastructure engineers and computing specialists to design and disseminate efficient bioimaging pipelines. "I'm very excited to be joining BioTechniques in this role, particularly at a time when the life sciences are rapidly evolving," Itano said. "I look forward to seeking ways that BioTechniques can further advance and support the effort to diversify and directly address inequalities in the publishing of biomedical techniques."

In parallel, BioTechniques has also launched BioTechniques LEARN to provide resources covering all the areas an early-career researcher needs to support them in their career. With guidance from a panel of mentors, BioTechniques LEARN will provide resources including career and mentorship guidance and tips for getting work published (and noticed) – all in addition to how-to guides for the essential methods needed in the lab, and the latest new protocols from the peer-reviewed pages of BioTechniques.

Best Practices and Tools for Reporting Reproducible Fluorescence Microscopy Methods

The rapid development of quantitative imaging technologies and analysis tools has enabled significant breakthroughs in life sciences and biomedical research. Rigorous and unbiased imaged-based experimental design and analysis workflows are critical to providing accurate insight into the biological process under investigation. However, this rapid development has presented new challenges for researchers, as an in-depth understanding of each technology is needed to appreciate how it may impact bias and reproducibility. Thus, even though microscopy methods reporting is a critical aspect of scientific communication, it is often overlooked throughout the peer-review process, often being condensed into one or two sentences that are missing critical details required to reproduce the experiments and lack appropriate citations.



Here <https://www.nature.com/articles/s41592-021-01156-w> four Light Microscopy Core Facility Directors, including Michelle Itano, PhD, (see article above) and their Staff (from UNC, Duke, Harvard, and Univ. of Minnesota) collaborated to present guidelines and other resources to educate and assist researchers at reporting for the most common fluorescence light microscope modalities: widefield microscope, single point scanning confocal microscopy, spinning disk confocal microscopy, and multiphoton microscopy. We showcase examples to demonstrate and highlight errors that can arise from insufficient reporting and provide resources to assist researchers with this task: an educational poster, comprehensive checklists and a customizable checklist-generating tool, called MicCheck. Our goal for these resources is not only to improve methods reporting during manuscript preparation, but to also influence the design of the experiment and image acquisition before data collection, ultimately improving the quality, rigor, and reproducibility of image-based science.

Pictured above: Best Practices and Tools for Reporting Reproducible Fluorescence Microscopy Methods poster in our Neuroscience Microscopy Core. Additional posters have been ordered following requests from investigators wanting poster for their own lab spaces on campus at Duke, NCSU, Princeton, the MBL, UT Dallas, China, Scotland, and the Netherlands.

Piven Appointed to Interagency Autism Coordinating Committee

The U.S. Department of Health and Human Services (HHS) announced the appointments of new and returning members to the Interagency Autism Coordinating Committee (IACC), a federal advisory committee reauthorized under the Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act of 2019.



Joe Piven, MD

Joseph Piven, MD, the Thomas E. Castelleo Distinguished Professor of Psychiatry and Pediatrics at the UNC School of Medicine, and Director of the Carolina Institute for Developmental Disabilities (CIDD), was appointed to the committee along with 21 other public experts in autism.

Piven, an international leader in the field of autism, is the principal investigator of the National Institutes of Health Autism Center of Excellence at UNC-Chapel Hill and member of the UNC Autism Research Center. He co-leads a multicenter research team using a five-year, \$9.5-million NIH grant to further evaluate whether brain imaging can help detect very high risk of autism spectrum disorder in early infancy. His team at CIDD also houses SPARK, a landmark research partnership between the Simons Foundation Autism Research Initiative (SFARI), UNC-Chapel Hill, and 31 other clinical and research institutions across the United States dedicated to helping individuals with autism and their families.

The IACC is a federal advisory committee composed of public stakeholders and federal officials that coordinates federal activities concerning autism spectrum disorder and provides advice to the HHS Secretary on issues related to autism. Committee meetings serve as a public forum for the sharing of community perspectives and concerns about autism. The committee uses this input as it formulates advice and recommendations for the HHS Secretary on matters related to autism research, services, and policy. The committee's responsibilities include developing and annually updating the IACC Strategic Plan for Autism Spectrum Disorder (ASD) and preparing an annual summary of Advances in ASD Research.

After an open call to the public for nominations of individuals to serve on the committee, Secretary of Health and Human Services, Xavier Becerra, JD, appointed 20 new and two returning public members to the IACC to provide him with advice to advance research, enhance services, and increase opportunities for people on the autism spectrum. The committee also includes 23 new and returning federal agency officials representing key federal agencies and departments that serve the autism community across a wide variety of areas, including biomedical research, healthcare, education, and social services.

Joshua Gordon, MD, PhD, director of the National Institute of Mental Health, will continue to serve as the chair of the committee. A full roster and biosketches of all the new and returning members can be viewed on the IACC website.

IACC Executive Secretary, Susan Daniels, PhD, stated, "We are excited to welcome the largest and most diverse IACC to date, with a wider representation of perspectives from across the autism community than ever before."

Expertscape Recognizes UNC School of Medicine Faculty as Top-Rated Experts in Angelman Syndrome



Ben Philpot, PhD

Expertscape, an online database that assesses and ranks the expertise and contributions of physicians and medical institutions worldwide, rated multiple UNC biomedical researchers and physicians as top-rated experts in their fields for its 2021 rankings. Expertscape ranks people and institutions by their expertise in more than 29,000 biomedical topics. The website bases its rankings on scientific publications, reviewing medical journal articles from the National Institutes of Health's PubMed journal database dating back to 2010. Each article is assigned a score based on a number of criteria, including the journal's prominence and the type of article.

Congratulations to Ben Philpot, PhD, who has been recognized as the number one expert in the world in Angelman syndrome. Philpot is the Kenan Distinguished Professor of Cell Biology & Physiology; Associate Director of the UNC Neuroscience Center and member of the Carolina Institute for Developmental Disabilities. The University of North Carolina was recognized as the number one institution with expertise in Angelman Syndrome worldwide.

Mark Zylka, PhD, W.R. Kenan, Jr. Distinguished Professor of Cell Biology & Physiology, was recognized as the number five expert in the world and U.S. in Angelman syndrome. Matthew Judson, PhD, research associate in the Philpot lab, was ranked as the fourth leading expert in Angelman syndrome.

Anna Ward and Kenneth Kelty Selected as Think College Policy Advocates



Anna Ward

Spring 2021, Anna Ward, Director of Advocacy and Inclusion at the CIDD, and Kenneth Kelty, CIDD Disability Advocate, were chosen to participate as a team in the Think College Policy Advocate program to represent UNC, and the programs in the UNC System. This program requires an application process, and 9 teams, made up of one student/alumni and one IPSE staff, are chosen from various inclusive postsecondary programs (IPSE). Think College and AUCD join forces each year to provide coaching, education, expert advice and to support the teams attendance at the Disability Policy Seminar, which is annually sponsored by nationally recognized organizations like AUCD, The Arc, AAIDD, Centers for Independent Living and Autism Society (to name a few). Each Think College team is provided with a coach who helps them contact their legislators, script, plan and rehearse meetings and joins them in speaking with members of Congress. Teams also have regular meetings with the Think College group, Denise Rozell and Liz Weintraub, who are policy advisors for AUCD. Liz Weintraub also is the host of "Tuesday's with Liz," which is AUCD's weekly videocast about disability policy.

Ward and Kelty jointly created a script and rehearsed with their coach, Siddarth Nagaraj, and met with education policy staff from the offices of both NC Senators Tillis and Burr, and Representatives Foxx and Ross. In each meeting Kelty told his story of how important his postsecondary education was at Western Carolina's UP program, and the CIDD LEND program. Ward discussed the efforts of the HEELS 2 Transition programming and the progress of UNCG and Appstate in their IPSE programs, as well as additional statewide legislative updates around disability and postsecondary education. Kelty was recently interviewed about his experiences as a Think College Policy Advocate on "Tuesdays with Liz". That interview can be found [here](#).



Kenneth Kelty on "Tuesdays with Liz"

The team presented to the NC Postsecondary Alliance about their experiences and continue to maintain relationships with their members of Congress. Kelty and Ward are available to do presentations for interested groups and can be contacted through Ward, at anna.ward@cidd.unc.edu.



HEELS UP participants with UNC's Chancellor, Kevin Guskiewicz.



HEELS Bridge Participants tour UNC campus.

HEELS **Higher Education, Employment, Living Success** **Transition** **Supporting individuals with intellectual disabilities transitioning to adulthood**

HEELS 2 Transition (H2T) 2021 wrapped up another impactful year of program expansion and replication, in both online and hybrid formats. This included the launch of HEELS Bridge, a program that supports college access and readiness for young adults with IDD; HEELS UP, the first-ever inclusive postsecondary program at UNC; the 3rd iteration of HEELS Prep, which supports skill-building in key areas of the transition to adulthood; and the launch of HEELS Alumni leadership program, a program offered to HEELS Prep alumni which furthers self-advocacy and leadership development.

H2T continues to work with UNC faculty and students to create an inclusive and accessible campus community for all. This year, H2T programs supported a total of 22 participants. H2T also provided mentorship and training in strengths-based approaches to 25 graduate student coaches, and involved 9 undergraduate peer supports.

H2T is an interdisciplinary collaboration between TEACCH, CIDD, UNC's School of Education, Division of Occupational Therapy, Division of Clinical Rehabilitation and Mental Health Counseling, and regional non-profit Fullpower North Carolina.

For more information, visit the H2T website:

<https://www.med.unc.edu/ahs/outreach/heels2transition/>

NC-LEND 2021-2022 Trainees and Fellows



Michelle Ballasiotes is a second-year master's student in occupational therapy. Her research and clinical interests include improving the quality of life for people with developmental disabilities across the life course, increasing participation in adaptive sports, and understanding romantic relationships for people with disabilities.



Breonna Caldwell is a second-year master's student at UNC-CH studying occupational therapy. Her clinical and research interests include the pediatric population, transitional services and post-secondary education for young adults with I/DDs, and diversity and inclusion in healthcare.



Erica Carter is a second-year doctoral student in school psychology at NCSU. Her research explores the contextual factors that impact social and emotional development in early childhood, specifically regarding peer relationships. Her clinical interests include pediatric neuropsychology, early detection and intervention, and differential diagnosis of intellectual and developmental disabilities. Erica is actively engaged in service to the psychology profession through developing and working on initiatives that address equity, diversity, and inclusion including recruitment and retention. This year her externship is at UNC's Rehabilitation Center where she will be assisting with neuropsychological evaluations to promote proper diagnosis and care coordination.



Alex Coffey is a third-year doctoral student in the Department of Maternal and Child Health in the Gillings School of Global Public Health. Alex's research interests include understanding how policies and systems can promote positive child development among children with developmental disabilities and their families.



Shannon Culbertson is a third-year doctorate in audiology student. Shannon hopes to work as a pediatric audiologist in a medical setting. She is passionate about family-centered care and looks forward to serving her patients with hearing loss and additional I/DDs.



Catherine Cunningham is a physical therapist completing her Pediatric Physical Therapy Residency at UNC-CH. Catherine's research and clinical interests include early mobility in critically ill children specifically in the cardiac intensive care unit, and working to create opportunities for independence in children with developmental disabilities.



Keiron Dyck is a self-advocacy fellow. In 2020, he completed the Scholars with Diverse Abilities Program at Appalachian State. The 2-year program aims to prepare college-aged students with intellectual disabilities for personal growth and occupational success. Keiron currently works at Wegmans. His goal in LEND is to learn and have opportunities to advocate for people with disabilities.



Logan Hartley is a fourth-year doctoral student in school psychology at UNC-CH. Logan's research interests include school-based mental health supports, inclusivity of LGBTQIA+ students within the school systems, and experiences of individuals on the autism spectrum who identify as LGBTQIA+. Her clinical interests involve the assessment and treatment of individuals with I/DD.



Sarah Holt is a LEND Family Fellow with a 5 year old son with Down syndrome. Sarah currently works as a full time mother to her two children. She previously worked as a plant biology researcher and has a PhD in Horticulture from Virginia Tech.



Sophie Hurewitz is a fourth-year undergraduate student at Duke University studying Neuroscience, Global Health, and Child Policy Research. At Duke, she is an Alice M. Baldwin Scholar, a researcher at the Duke-Margolis Center for Health Policy, a member of a Bass Connections team working to fulfill the goals of the North Carolina Early Childhood Action Plan, and a researcher for the Path for Children's Complex Care Coalition of NC (Path-4CNC) team. She is also a member of the Society for Developmental & Behavioral Pediatrics and the 2021-2023 Student Representative for Academy Health's Child Health Services Research Interest Group. She plans to become a developmental-behavioral pediatrician to combine her interests in clinical medicine, health policy, education policy, family advocacy, and child and adolescent development.



Leigh Anne Jackson is a second-year master's student at UNC's Division of Occupational Science and Occupational Therapy. Leigh Anne's research and clinical interest include deinstitutionalization and community integration for individuals with I/DD. She is also interested in OT's role in supporting caregivers and promoting self-determination.



Amanda Jones is a third-year doctoral student in school psychology at NCSU. Her current research and clinical interests include the connection between wellness and body image on the mental health of LGBTQ+ youth, food distribution services and policy for children in US school systems, and the prevention of burn out through supportive self-care strategies for adults who care for children.

NC-LEND 2021-2022 Trainees and Fellows *continued*



Jane Khin is a third-year audiology doctoral student and LEND trainee at UNC-CH. Jane is interested in providing accessible, comprehensive audiologic care to patients across the lifespan, with an emphasis on serving populations with hearing loss alongside other neurodevelopmental conditions. She also hopes to integrate clinical research into her future work, focusing on the intersections between audiology and public health.



Bryan Reed is an MSN student in the Psychiatric-Mental Health Nurse Practitioner program at UNC-CH. He is a UNC Currie Scholar. Bryan has prior work experience with TEACCH, as well as inpatient and outpatient psychiatry with children and adults. He hopes to improve outcomes for individuals with developmental disabilities and is particularly interested in the emerging research regarding the use of cognitive behavioral therapy (CBT) to reduce anxiety in individuals with ASD.



Danielle Manning is a second-year graduate student in the Speech-Language Pathology master's program at North Carolina Central University. Her clinical interest includes early intervention, pediatric speech and language disorders and working with children with Intellectual and developmental disabilities. She hopes to serve as an advocate in her field for children and families living with developmental disabilities.



Lisbeth Rivera is a LEND Family Fellow. She is a graduate of UNC-CH with a Bachelor's in Psychology and is currently working as a paralegal. As a native Spanish speaker, she is interested in community outreach for the Hispanic community and exploring a future career in public health.



Tyler McFayden is completing her doctorate in clinical and developmental psychology and is the current intern at the CIDD. Tyler's research and clinical interests include language and social communication in neurodevelopmental disorders, early assessment and intervention services for autism spectrum disorder (ASD), and complex medical comorbidities of ASD, including hearing loss and genetic syndromes.



Kim Schlegel is in the final year of UNC's MSW distance education program. She works full-time as a care navigator for individuals with intellectual and developmental disabilities (IDD). Prior to becoming a care navigator, she practiced music therapy, where she facilitated music therapy and social skills groups for individuals of varying ages with varying abilities. Kim's professional and research interests include interdisciplinary team approach, provision of and access to health care, access to appropriate and necessary support services, and policy regarding individuals with IDD.



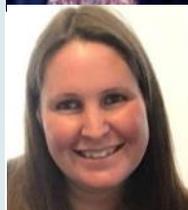
Stephanie Ortega is a third-year Doctor of Audiology student at UNC-CH. She graduated cum laude from the University of Florida with a Bachelor's of Science in Communication Sciences and Disorders. Stephanie is a LEND trainee and has a special interest in children who are Deaf+. She is a certified Spanish interpreter and hopes to pursue a career in pediatrics especially with bilingual patients.



Hannah Schroyer is a second-year Speech-Language Pathology student at UNC-CH. Her research and clinical interests include facilitating interdisciplinary collaboration, promoting educational equity and accessibility, and providing culturally and linguistically responsive services.



Alexa Prass is a second-year master's student in the combined public health and dietetics program in Gillings School of Global Public Health. Alexa is studying to become a registered dietitian. Alexa's interests include nutrition counseling, personalized nutrition, weight-inclusive care, and Celiac Disease.



Jennifer Snow is a family fellow in the LEND program. She has two children, a three year old and a nine year old. Jennifer's youngest child has autism and her oldest child has ADHD. She is an Education Coordinator for a local HS/EHS program.



Orla Putnam is a second-year doctoral student in Speech and Hearing Sciences. Orla's research interests include autistic communication, "masking" of autistic traits and its impact on mental health, and examining what autism looks like in females and other underrepresented genders.



Katie Sobon is a third-year audiology student at UNC-CH. She earned a BA in Linguistics and a BA in Interpersonal/Organizational Communication Studies also from UNC. Katie is interested in working with children with developmental disabilities in addition to hearing loss. In particular, she aims to improve early identification and diagnosis of hearing loss in children with developmental disabilities.

NC-LEND 2021-2022 Trainees and Fellows *continued*



Katie Visconti is a final year Social Work graduate student. Her research and clinical interests include addressing systemic barriers to access, advancing equity in outcomes, and deinstitutionalization efforts in North Carolina.



Asantewaa "Yaa" Yamoah is a final year master in social work student at UNC-CH. Yaa's clinical interests include assessment of autism spectrum disorder, sexual health education of people with IDD, supporting the IDD community in navigating the healthcare system, and Dialectical Behavior Therapy (DBT) for the IDD population.



Megan Weible is a first-year genetic counseling student at UNC-Greensboro. Megan's clinical and research interests include metabolic genetics, promoting autonomy within pediatric patient populations, and exploring the intersection of professional and personal identities among disabled health care professionals.

Former NC LEND Trainee Named AUCD "Emerging Leader"



Jacklyn Googins, recent NC LEND and OT graduate from the UNC Division of Occupational Science and Occupational Therapy Program, was a recipient of AUCD's "Emerging Leader" award for the state of North Carolina. This award is a national recognition that features the contributions of diverse trainees enacting innovative work across AUCD's network with this year's theme of "Promoting Health Equity: Identifying Access Barriers and Protecting Rights to Services for People with Disabilities." The purpose of this award is to showcase the many diverse ways that emerging leaders are working to enhance access for people with disabilities and facilitate dialogue and collaboration between centers. For her 2021 LEND project, Jacklyn developed a program offered through the HEELS 2 Transition organization called HEELS Bridge, which promotes college readiness and access for young adults with I/DD. Through an emphasis on self-determination and occupational justice, the program equips participants to navigate the "hidden curriculum" of higher education.

Broadly, Jacklyn's areas of interest and experience include diversity and inclusion in the workplace, post-secondary transition planning for adolescents/adults with I/DD, universal design, accessibility in higher education, and pro-neurodiversity, identity-affirming therapeutic approaches. Jacklyn is the founder/director of B3 Coffee, a local nonprofit that provides community-integrated social and vocational opportunities for people of all abilities (b3coffee.org).

Let's Talk: Sexuality and Relationship Education for Youth with I/DD and Their Caregivers

CIDD is pleased to be offering our fall session of Let's Talk: Sexuality and Relationship Education for Youth with I/DD and Their Caregivers.

This series focuses on human development, social skills/boundaries, internet and social media safety, steps to relationship, sexual health self-advocacy and on personal safety and violence prevention. This 6 week series will be held, virtually through Zoom. Facilitators are Margaret DeRamus, MS, CCC-SLP, and Morgan Parlier, MSW, LCSW.

We are recruiting families who are interested in participating in this series, which will occur on Tuesday evenings from 6:00-7:30 pm from November 2nd through December 7th.

For more information, contact Yaa.Yamoah@cidd.unc.edu or (919) 843-8122 by October 31st, 2021

Topics Include:

- Sexual Development
- Anatomy & Physiology
- Healthy Relationships
- Safety & Boundaries
- Sex, Laws & Staying Healthy
- Safer Sex

2021 CIDD "Virtual" Community Talk Series

All are welcome! Join us to learn about recent advances in developmental disabilities. FREE!

Meetings via ZOOM - Time: 6:30 – 8:00 pm FREE!



November 10, 2021

Brittney Black, MS, CRC, LCMHC, LCAS-A
Vocational Rehabilitation Counselor in Charge

Rebecca Evans, MEd, CRC, CPM
Vocational Rehabilitation Unit Manager

"Vocational Rehabilitation: What Families of Individuals with I/DD Need to Know"

Speakers will provide an overview of Vocational Rehabilitation (VR) Services and discuss the various services that are available to middle and high school students.



December 8, 2021

Donna Beckman
Advocacy and Outreach Director, North Carolina Down Syndrome Alliance

"Personal Empowerment: Having your Voice Heard from the Schoolhouse to the Statehouse"

Learn how to tailor your message to deliver it effectively and efficiently. Be part of the solution instead of part of the problem.

For more information, contact: Debbie B. Reinhartsen, PhD, CCC-SLP Debbie.Reinhartsen@cidd.unc.edu / 919-966-4138
Virtual Attendance Certificates—Professional Development 1.5 Credit Hours are available for each talk

Administration for Community Living COVID 19 Vaccination Efforts

Disparities between persons with disabilities obtaining COVID 19 vaccinations and the rest of the population lead the Administration for Community Living (ACL) to support Developmental Disability Network organizations through grants to provide education and access within their states to individuals and their families.

The CIDD, NC Council on Developmental Disability (NCCDD), and Disability Rights NC (DRNC) were each awarded funding. DRNC has taken the lead with the collaborative through Project ACCESS (All Communities Count Equitably for Safety and Support). ACCESS Director, Curtis Hill, and team go into NC counties with low rates of vaccination, and provide education, outreach and access by partnering with providers and local organizations. So far they have been to 3 counties with plans to reach individuals from all 100 counties in the state. NCCDD has supported an Ambassador program which will utilize Peer Mentors who assist Project ACCESS in education and outreach.

The CIDD has connected with UNC Health, to determine communities served within the health system that have low vaccination rates, and intends to provide education for those regions about the special considerations around vaccination in the disability community. The September 2021 CIDD Community Talk featured a panel of vaccinated Self Advocates, their families, as well as Hill from Project ACCESS, Jacob Bridges from Alliance of Disability Advocates NC (ADANC), and Dr. Joshua Gettinger MD, parent and member of NCCDD, all speaking about their experiences with COVID, the vaccine, as well as addressing concerns and questions from attendees. The link to view the Community Talk Panel can be found on the CIDD Community Talk Series webpage: <http://www.cidd.unc.edu/Education/CommunityTalk/2021CommunityTalkSeries.aspx>



Stories were also collected on video from self advocates to be featured as part of the #AUCDSleeveUp campaign competition. Emma Miller and Kenneth Kelty created short videos promoting the vaccine. Kelty had the highest votes, winning himself and his mother, Jackie Kelty, a spot on the "Tuesdays with Liz" YouTube series (pictured left). Watch Kelty's winning video at this link: <https://www.youtube.com/watch?v=XyBitECKyAM>

CIDD and their partners will continue to provide updates on the vaccination efforts. If you or someone you know needs access, you can use the form from the ADANC at this link: <https://adanc.org/vaccine/> or email anna.ward@cidd.unc.edu.



**Need a free ride to your
COVID-19 vaccine appointment?**

CALL 1-844-771-RIDE TODAY

United Way, Lyft Providing Free Rides to COVID-19 Vaccination Sites Across North Carolina

Despite the increasing availability of the COVID-19 vaccine in North Carolina, transportation access continues to be a barrier for underserved communities statewide. The RIDE UNITED NC call center is available to support low-income North Carolina residents needing roundtrip transportation to COVID-19 vaccine appointments. Eligible individuals can call 1-844-771-RIDE starting today.

The statewide initiative was launched by United Way of the Greater Triangle in partnership with Lyft, Blue Cross and Blue Shield of North Carolina (Blue Cross NC), and North Carolina Department of Transportation (NCDOT), in support of the North Carolina COVID-19 Public Health Coalition.

The call center has the capacity to support 1,500 calls per day for eligible individuals who do not have access to the Lyft app, those without bank accounts, and seniors. It will also work with NCDOT to supplement transportation needs in other communities. The call center is/has:

Available Monday through Friday, 8 am to 8 pm with Bi-lingual capabilities .

Open to those who are age 55+, uninsured, unbanked, and/or members of households considered low-income by the federal definition.

To learn more visit: <https://www.unitedwaytriangle.org/rideunitednc/>

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 Carolina Institute for Developmental Disabilities 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.

Send us your comments or sign up to receive the newsletter: info@cidd.unc.edu

Newsletter Editor—Keath Low, MA