Dr. Rebecca Edmondson Pretzel Named Associate Director of the Carolina Institute

The Carolina Institute for Developmental Disabilities (CIDD) is pleased to announce the appointment of Rebecca Edmondson Pretzel, PhD as the new Associate Director of the Institute.

Dr. Pretzel is a psychologist and Associate Professor of Psychiatry. At the CIDD, she serves as the Associate Director of our federally-funded University Center of Excellence in Developmental Disabilities (UCEDD) program, Director of Clinical Services, and Psychology Section Head. In addition, she is an investigator on a variety of research and training grants and supervises numerous graduate students and junior faculty.

Through her longstanding experience working with many N.C. service agencies (e.g., the Department of Public Instruction, Early Intervention Branch and Division of MH/DD/SAS), Dr. Pretzel has played an important role in raising the level of care for individuals with developmental disabilities and their families in the state.

Dr. Pretzel is currently serving as Act Early Ambassador in North Carolina, a program directed by the Centers for Disease Control and Prevention designed to improve early identification of young children with or at risk for developmental delays. CIDD Director, Joe Piven, M.D., noted that “we are extremely fortunate to have such an experienced and capable person to take on this important role at the CIDD”. Dr. Pretzel replaces Dr. Stephen Hooper who was recently appointed Chair of the Department of Allied Health Sciences at UNC.

UNC to Launch Unprecedented Collaboration to Improve Services for Young Children with Autism and Their Families

Researchers at the University of North Carolina at Chapel Hill have received a State Implementation Grant of $900,000 from the Maternal and Child Health Bureau of the U.S. Department of Health and Human Services to improve services for young children with Autism Spectrum Disorder (ASD) and their families.

This three-year project has the primary purpose of linking both university and state partners to lower the ages by which young children receive appropriate developmental screening, ASD-specific screening, diagnostic assessments, and early intervention. North Carolina was one of only four states to be awarded funding by the Bureau during this cycle, and this initiative is one of the first to involve nearly all of the major ASD programs on UNC’s campus.

The grant is under the directorship of Stephen Hooper, PhD, Associate Dean and Chair of the UNC School of Medicine’s Department of Allied Health Sciences (DAHS), and in collaborative leadership with Rebecca Edmondson Pretzel, PhD, Associate Director of the Carolina Institute for Developmental Disabilities (CIDD).

Continued on page 2
In addition to its primary goals, this grant will allow researchers to examine strategies to increase access of families to family-centered medical homes that coordinate care with pediatric subspecialties, increase public and provider awareness of the signs and symptoms of ASD, and complete a statewide needs assessment addressing family needs and barriers to coordinated care.

To accomplish the grant’s objectives, DAHS and CIDD collaborators have enlisted the expertise of key UNC programs with a major focus on ASD, including the AHEC TEACCH Program, Frank Porter Graham Child Development Institute, the Gillings School of Global Public Health, the School of Social Work, and the Cecil G. Sheps Center for Health Services Research.

“While this is certainly not the first project where various programs have collaborated on issues of ASD, it is the first project where programs have collaborated around improving the coordination of state services to children suspected of having ASD and their families,” Dr. Hooper said. “We are fortunate to receive these additional resources from the Maternal and Child Health Bureau, and excited about this opportunity to enlist the expertise of our UNC partners and key state agencies, such as the Autism Society of North Carolina, the state of North Carolina Early Intervention Program, and the North Carolina Department of Public Instruction pre-kindergarten programs, in addressing these ASD-related needs across the state.”

A key component of this program will be assessing the needs of families from across the state, particularly with respect to their experiences with early screening, diagnostic assessments, and early intervention. Increasing public awareness of the early signs and symptoms of ASD also will be an annual objective, with significant efforts being devoted to rural and underserved regions of the state and examining the pathways by which families have access to the necessary services to address their child’s medical and developmental needs.

“The state of North Carolina is fortunate to have a number of service systems in place to address the needs of young children with developmental disabilities and their families,” said Dr. Edmondson Pretzel. “We are confident that this new funding will enhance current efforts and facilitate additional improvements for young children with ASD and their families.”

For additional information pertaining to the newly awarded ASD State Implementation Grant, please contact Dr. Stephen Hooper, Associate Dean and Chair of the Department of Allied Health Sciences (Stephen_Hooper@med.unc.edu) or Dr. Rebecca Edmonson Pretzel, Associate Director of the Carolina Institute for Developmental Disabilities (Becky.Edmondson@cidd.unc.edu).
Hearing and Development Clinic Featured at Conference

CIDD’s Hearing and Development Clinic was featured at the Annual Convention of North Carolina’s Alexander Graham Bell Association in cooperation with the Carolina Children’s Communicative Disorders Program, November 7th and 8th, 2013. The Hearing and Development Clinic was established at CIDD in 2011 by professionals with expertise in audiology, speech-language pathology, psychology, education, and physical/occupational therapy to provide an interdisciplinary assessment of children with hearing loss when families or service providers suspect additional challenges or disabilities. It is the only team of its kind in North Carolina. The conference, now in its 20th year, was attended by professionals from across the state who serve children with hearing loss and their families.

Speech-language pathologist Margaret Deramus describes diagnostic criteria for autism spectrum disorders used in the Hearing and Development Clinic at CIDD. Other CIDD presenters included (L-R) Emily Kertcher (occupational therapy), Jean Mankowski (psychology), and Jackson Roush (audiology). Not shown, Kathryn Wilson (speech-language pathology).

Supporting Rural Families with Toddlers on the Autism Spectrum

The Family Implemented TEACCH for Toddlers study (FITT, renamed from Home TEACChing Program to emphasize the project's relationship with families) recently finished its second of three funded years. Based on structured teaching and naturalistic strategies, this family-implemented approach provides coaching and support for families to increase interaction and engagement with their young children with ASD across daily routines. Interventionists provide 24 weekly sessions held across a 6-month intervention time period, which include four clinic-based parent group sessions (3 families per group) plus 20 in-home intervention sessions. FITT introduces families to the concepts of structured teaching, and provides families a set of strategies for working, playing, and communicating with their toddler.

FITT has an emphasis on serving rural families, with 18 of our 39 families (46%) who have completed the intervention or are currently enrolled, living in rural communities. The study process and intervention have been designed to allow access and participation to families who are often underserved. Partnerships have been formed with rural regional intervention centers, with information and resources provided related to early identification, assessment, and the benefits of early intervention for children with ASD and their families. Diagnostic assessments are also offered to participating families. Intervention is offered in-home to support families with limited transportation, and intervention is provided during non-traditional hours (e.g. evenings, early mornings, weekends) to align with varied work schedules. All families, those assigned to the intervention group (FITT) and the services-as-usual group (SAU) are provided with information about local resources to ensure access to ongoing support.

Early data related to intervention acceptability and feasibility (e.g. Did rural families like the intervention? Could the intervention be implemented well by project interventionists with rural families? Were rural families able to implement the FITT strategies?) are positive and promising. All rural families enrolled in the intervention have successfully completed; parents have been highly satisfied with FITT goals, procedures, and perceived child outcomes; and both interventionists and families are able to implement the strategies with fidelity.

Intervention in rural and non-rural communities is ongoing, and will be completed in August 2014. Analyses of the impact of the FITT intervention on family outcomes and child outcomes will be conducted, as well as an analysis of the feasibility and acceptability of the intervention in both rural and non-rural communities. If effective, the FITT intervention will be shared with our rural partners for broader dissemination.

FITT is an inter-disciplinary project, led by Co-PIs Dr. Lauren Turner-Brown, clinical psychologist, and Dr. Kara Hume, special educator, housed at the CIDD. Project staff includes social workers, allied health professionals, and a number of student and community volunteers. For more information about the project, please contact Project Coordinator Cassidy Arnold, at cassidy.arnold@cidd.unc.edu.
UNC Neuroscientists Discover New ‘Mini-Neural Computer’ in the Brain

Dendrites, the branch-like projections of neurons, were once thought to be passive wiring in the brain. But now researchers at UNC have shown that these dendrites do more than relay information from one neuron to the next. They actively process information, multiplying the brain’s computing power.

“Suddenly, it’s as if the processing power of the brain is much greater than we had originally thought,” said Spencer Smith, PhD, a CIDD investigator and assistant professor in the UNC School of Medicine. His team’s findings, published in the journal *Nature (October 27, 2013)*, could change the way scientists think about long-standing scientific models of how neural circuitry functions in the brain, while also helping researchers better understand neurological disorders.

Axons are where neurons conventionally generate electrical spikes, but many of the same molecules that support axonal spikes are also present in the dendrites. Previous research using dissected brain tissue had demonstrated that dendrites can use those molecules to generate electrical spikes themselves, but it was unclear whether normal brain activity uses those dendritic spikes. For example, could dendritic spikes be involved in how we see?

The answer, Smith’s team found, is yes. Dendrites effectively act as mini-neural computers, actively processing neuronal input signals themselves.

Directly demonstrating this required a series of intricate experiments that took years and spanned two continents, beginning in senior author Michael Hausser’s lab at University College London, and being completed after Smith and Ikuko Smith, PhD, DVM, set up their own lab at the University of North Carolina. They used patch-clamp electrophysiology to attach a microscopic glass pipette electrode, filled with a physiological solution, to a neuronal dendrite in the brain of a mouse. The idea was to directly “listen” in on the electrical signaling process.

“Attaching the pipette to a dendrite is tremendously technically challenging,” Smith said. “You can’t approach the dendrite from any direction. And you can’t see the dendrite. So you have to do this blind. It’s like fishing but all you can see is the electrical trace of a fish.” And you can’t use bait. “You just go for it and see if you can hit a dendrite,” he said. “Most of the time you can’t.”

But Smith built his own two-photon microscope system to make things easier.

Once the pipette was attached to a dendrite, Smith’s team took electrical recordings from individual dendrites within the brains of anesthetized and awake mice. As the mice viewed visual stimuli on a computer screen, the researchers saw an unusual pattern of electrical signals – bursts of spikes – in the dendrite.

Smith’s team then found that the dendritic spikes occurred selectively, depending on the visual stimulus, indicating that the dendrites processed information about what the animal was seeing. To provide visual evidence of their finding, Smith’s team filled neurons with calcium dye, which provided an optical readout of spiking. This revealed that dendrites fired spikes while other parts of the neuron did not, meaning that the spikes were the result of local processing within the dendrites.

Study co-author Tiago Branco, PhD, created a biophysical, mathematical model of neurons and found that known mechanisms could support the dendritic spiking recorded electrically, further validating the interpretation of the data. “All the data pointed to the same conclusion,” Smith said. “The dendrites are not passive integrators of sensory-driven input; they seem to be a computational unit as well.”

His team plans to explore what this newly discovered dendritic role may play in brain circuitry and particularly in conditions like Timothy syndrome, in which the integration of dendritic signals may go awry.
**Understanding Clinical Problems in Older Adults with ASD and ID**

Originally described as a disorder of childhood, evidence now demonstrates the lifelong nature of autism spectrum disorder (ASD). Despite the increase of the population over age 65, older adults with ASD remain a scarcely explored subpopulation.

CIDD researchers investigated the prevalence of clinically relevant behaviors and medical problems in a sample of US adults aged 30 to 59 with ASD and intellectual disability (ID), in comparison to those with ID only. The study, “Prevalence of selected clinical problems in older adults with autism and intellectual disability,” is published in the Journal of Neurodevelopmental Disorders (Sept 25, 2013).

This large-scale, systematic study was designed to examine clinical problems in older adults with ASD and ID. Adults with both ASD and ID constitute those individuals with ASD likely to have the greatest degree of difficulties, and therefore are likely to provide insights into the need for treatment of this group of individuals (who have largely been neglected in the research literature).

Findings highlight the urgent need for research on the nature of severe behavior problems in this rapidly increasing population of older adults. They also suggest the importance of developing policies that expand our capacity to care for these individuals through further research on this topic and training of clinical providers.

**Spreading the Word: Students with Intellectual Disabilities Can Succeed in Higher Education**

Opportunities for students with intellectual/developmental disabilities (ID) to participate in inclusive higher education continue to grow across North Carolina. This is good news for the NC Postsecondary Education Alliance (PSEA), a stakeholders group working to expand options, but many more opportunities are needed. Only about 100 students are served by these innovative options; the vast majority of young adults with ID never attend postsecondary education. Many families, students, educators, and employers are unaware of the positive outcomes of a postsecondary experience and the PSEA wants to change that.

PSEA member Duncan Munn has convened a new committee with a strategic focus on increasing public awareness. Munn is known for his innovations in the disabilities field; he is recognized for starting one of the first community early intervention (EI) programs in North Carolina.

He served as a local and regional coordinator for services for children and adults with developmental disabilities and as the Chief of Community Support Services for the NC Division of Mental Health/Developmental Disabilities/Substance Abuse Services.

Munn has kept up with many of the children and families supported in EI over the years and takes pleasure in supporting opportunities for EI “alumni” as current PSE students. When Munn became aware of limited options for these potential students, he became involved in the Beyond Academics (BA) program at UNC, Greensboro. Munn now chairs the private, non-profit BA board that partners with the University to operationalize and administer this initiative.

The NC PSE Alliance is supported by CIDD and cofacilitated by faculty members Donna Yerby and Deborah Zuver.
The CIDD has been hosting a series of talks to share information about recent advances in developmental disabilities. These sessions are a great opportunity for parents, teachers, professionals, and others to learn more about specific developmental disabilities topics. All talks are free, and everyone is welcome.

**2014 CIDD Community Talk Series**

Join us to learn about recent advances in developmental disabilities.

Sessions are held from 7PM to 8:30PM at the CIDD.

To RSVP or for more information, please contact Debbie B. Reinhartsen at (919) 966-4138 or Debbie.Reinhartsen@cidd.unc.edu

---

**Wednesday, February 12**

**Jennifer Mahan**  
*Director of Advocacy and Public Policy*

**Understanding Services: Navigating the Service System and Finding Help for Your Child or Client on the Autism Spectrum**

Jennifer Mahan has worked for the Autism Society of North Carolina for three years, in legislative, grassroots and one-on-one advocacy. Her background is in consumer advocacy, information and referral programs, and human services policy focused on developmental disabilities, mental health, addiction, and low-income benefits programs, including 10 years with the Mental Health Association in North Carolina.

The presentation will briefly cover the North Carolina autism service system including funding for services, who qualifies, Medicaid, managed care, getting help, and gaps.

---

**Wednesday, April 9**

**Susan Wright Kermon**  
*Self-Advocate, LEND Trainee*

**Kim Shufran**  
*Executive Director & Founder of iCan House*

**“There is Nothing Wrong with Me After All!”**

Susan was diagnosed with Autism Spectrum Disorder at age 45 by TEACCH. She graduated from UNCG with a BFA in Sculpture and has made a living as a decorative painter. She is now actively involved with the iCan House of Winston Salem and the CIDD in Chapel Hill.

When learning her daughter had Asperger's, Kim was dismayed at the notion that such children were "less than" others. Recognizing the gap in the community for programs that teach and foster social development, Kim designed and opened iCan House. Now in its 6th year, over 100 families come every week from 13 counties for their programs.

From “Autism Awareness” to understanding and acceptance: This is an important goal for individuals on the spectrum, their families, their communities and mainstream culture at large. Susan and Kim offer a unique combination of insights that address this issue at every level.

---

**Wednesday, May 14**

**Margaret DeRamus, MS, CCC-SLP**  
*Speech Language Pathologist/Clinical Scientist*

**The Language-Literacy Connection: Strategies for Promoting Language and Literacy Skills in Children with Developmental Disabilities**

Margaret DeRamus is a speech language pathologist at CIDD, who participates in a variety of clinics and several research projects related to autism spectrum disorders, Fragile X, Angelman syndrome, and Turner syndrome. Other areas of interest include Augmentative and Alternative Communication (AAC) and literacy.

This presentation will describe the connections between spoken language and literacy skills and provide strategies for promoting literacy skills for children with developmental disabilities.

Sessions are held from 7PM to 8:30PM at the CIDD.
AACAP George Tarjan Award for Contributions in Developmental Disabilities

CIDD Director, Joe Piven, M.D., is the 2013 recipient of the American Academy of Child and Adolescent Psychiatry (AACAP) George Tarjan Award for Contributions in Developmental Disabilities. The Award recognizes a child and adolescent psychiatrist and AACAP member who has made significant contributions in a lifetime career or single seminal work to the understanding or care of those with mental retardation and developmental disabilities. The award was established in 1993 in honor of AACAP past president (1977–79) George Tarjan, M.D., by his wife, Mrs. George Tarjan and friends. Dr. Piven was presented the award at the AACAP 60th annual meeting in Orlando, Florida.

Congratulations to Sam Odom
Recipient of the Arnold Lucius Gesell Prize

The Theodor Hellbrugge Foundation has awarded Samuel L. Odom the 2013 Arnold Lucius Gesell Prize for an outstanding career in the field of child development. Noting Odom’s "extraordinary contributions" in research and service, the foundation presented him with the award at an international conference convened to celebrate the prize.

Dr. Odom is the Director of the Frank Porter Graham Child Development Institute, Professor in UNC’s School of Education, and a CIDD/IDDRC Investigator whose distinguished career has focused most recently on studying autism spectrum disorders (ASD).

Dr. Odom’s recent work has addressed the effectiveness of a variety of approaches for children with ASD, including peer-mediated interventions, independent work systems, and other strategies and techniques. He currently heads the pioneering Center on Secondary Education for Students with Autism Spectrum Disorders, which is developing a comprehensive treatment model specifically designed for high school students—the first of its kind.

“It's an exciting time to focus on children with ASD," said Odom. “The research on the most effective behavioral and social interventions for these children is accelerating—and so are our understandings of how best to translate and implement these approaches in homes, schools, and communities.”

The Gesell Prize carries an award of 10,000 euros, a medal forged in silver, and a legacy alongside the international leaders in child development research. Only a dozen others had received the award before Odom.
2014 CIDD Investigator Forum

presents

Mark Zylka, Ph.D.
Department of Cell Biology and Physiology
University of North Carolina at Chapel Hill

“Gene Length Matters in Autism”

Tuesday, February 11th
12:15 p.m. – 1:30 p.m.

Location:
UNC Chapel Hill - Campus
Bioinformatics Building Room 1131
130 Mason Farm Road
Chapel Hill, NC 27599

Please save the following dates for the 2014 CIDD Investigator Forums

Tuesday, March 18th
12:15 p.m. – 1:30 p.m.
"A Genetic Approach to Understanding the Etiology of Autism"
Stephan Sanders, Ph.D.
School of Medicine
Yale University
*Joint CIDD/Neuroscience Center

Tuesday, April 8th
12:15 p.m. – 1:30 p.m.
"Translational Therapeutic Design for Fragile X Syndrome"
C. J. Malanga, MD, Ph.D.
Department of Neurology, Child Neurology, Movement Disorders
UNC - Chapel Hill

Tuesday, May 13th
12:15 p.m. – 1:30 p.m.
Topic To Be Determined
Ricardo E. Dolmetsch, Ph.D.
Allen Institute for Brain Science
Department of Neurobiology
Stanford University
*Joint CIDD/Neuroscience Center

Talks are free and open to the public
No pre-registration is required
Parking vouchers for the Dogwood Deck are available
Lunch served at 12:00

Questions contact:
Gabriel Dichter, Ph.D.
(919) 681-3169 | dichter@med.unc.edu
Adrienne Villagomez, this year’s CIDD Trainee Liaison was awarded the AUCD Trainee Travel Scholarship to attend this year’s AUCD Annual Conference. Adrienne is a psychology trainee at the CIDD and former LEND Special Education trainee. She presented a poster on behalf of other CIDD trainees, Megan Kovac (Psychology), Keith Errickson (Public Health), and Chris Cordeiro (Self-Advocacy), which described the success and impact of the LEND Self-Advocacy traineeship on CIDD-LEND trainees through data from an internal evaluation.

Adrienne also presented a poster with Deb Zuver, MA, LMFT, Angela Rosenberg, PT DrPH and Donna Yerby MEd entitled, “Postsecondary education for students with ID (PSE) as a catalyst for inclusion: Areas of involvement.” The purpose of this poster was to share information about inclusive higher education and creating university systems change in North Carolina. At the conference, Adrienne also participated in the Minority Partnerships meeting and a Postsecondary Education Special Interest Group with CIDD faculty.

Arc of NC Video Featuring Former CIDD LEND Trainee and Self-Advocate, Kira Fisher, Goes Viral!

Past LEND trainee, Kira Fisher, was featured in a video created by the Arc of North Carolina that debuted a couple of years ago to increase advocacy and understanding around Social Security for individuals with disabilities. The video is having an even greater impact than anticipated, according to Erika Hagensen, assistant director for policy at the Arc of North Carolina. Not only was it used to brief Congressional staff last year, with over 3,000 views, but today it’s gone viral.

Kira Fisher was selected to join the cohort of LEND trainees in the first year that advocacy was included as a represented discipline. LEND (Leadership Education in Neurodevelopmental & Related Disabilities) is funded by the US Bureau of Maternal and Child Health. The cohort comprises masters and doctoral students in an interdisciplinary training experience. Including advocacy expands the diversity of the group which currently includes a parent trainee. Kira gained leadership tools as she enriched the program with her own personal experience as a self-advocate. As coordinator for Youths 4 Advocacy (Y4A), Kira had previously supported self-advocacy and leadership at the CIDD for four years.

Watch Video: Kira’s Story
http://www.youtube.com/watch?v=vqlkPCV7h5w
Congratulations to Kylee Miller who recently defended her dissertation “Weighing in on the Relationship Between Macronutrient Intake, Weight Status, Cognitive Functioning, and Academic Performance In School-Aged Children.” This study found that 6-8 year-old children in the underweight range performed better than children in the overweight and obese ranges on all cognitive and academic tasks. Adolescents BMI’s in the normal weight range performed better than their peers in the underweight and obese weight ranges. These findings suggest that BMI and nutritional intake are associated with cognitive and academic performance, particularly during adolescence. The study provides support for the adverse relationship between underweight or obese weight status on cognitive and academic performance. Dr. Miller will continue to work at the CIDD during a two-year fellowship involving research on decisional capacity in fragile X syndrome, and participation in the diagnostic clinics.

Laura Brown and Melissa Scales, both physical therapists with the LEND Fellowship will be joining Kathleen Ollendick, PT, DPT, PCS and a group of UNC-Chapel Hill physical therapy students and faculty members in Antigua, Guatemala in April 2014 as part of UNC PT Outreach designed to work with underserved populations and increase cultural competency among physical therapists.

Kathleen Ollendick, PT, DPT, PCS, faculty advisor to the PT LEND Fellowship; Laura Brown, PT, DPT; Sarah Scow, PT, DPT; and Melissa Scales, PT, DPT, physical therapists with the LEND Fellowship will be representing UNC-CH and the CIDD at the American Physical Therapy Association's Combined Section Meeting in February 2014 in Las Vegas, NV with a poster presentation, “Identification of Falls Incidence, Risk Factors, and Causes in Individuals with Intellectual and Developmental Disabilities.”

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

A text only version of the newsletter in Word is available.