



Inside the Institute

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North Carolina Autism Research Registry Used for Statewide Service Planning

The North Carolina Autism Research Registry, established in 2001 at the Carolina Institute for Developmental Disabilities, is a database of individuals with a confirmed autism spectrum disorder (ASD) diagnosis who have consented to be notified about current research studies. Having a systematic way to identify and contact potential research participants provides a powerful advantage to mobilize research quickly and accelerate the progress in understanding and treating ASD.



Currently, there are more than 6,000 people from across North Carolina enrolled in the NC Autism Research Registry. It is one of few autism registries and the largest statewide ASD registry in the country. It has been established through the successful collaboration of the CIDD Intellectual and Developmental Disabilities Research Center (IDDRC), the UNC TEACCH Program, many state and local service providers, and advocacy organizations (ASNC, Autism Speaks). Funding for the NC Autism Research Registry is provided by the National Institute of Child Health and Human Development (NICHD).

Since its founding, the Registry has supported more than 75 research projects on a variety of topics including brain development, brain functioning, early identification, sensory features, repetitive behavior, language development, parent support, risk factors for ASD, behavioral intervention and clinical trials. Recently, the

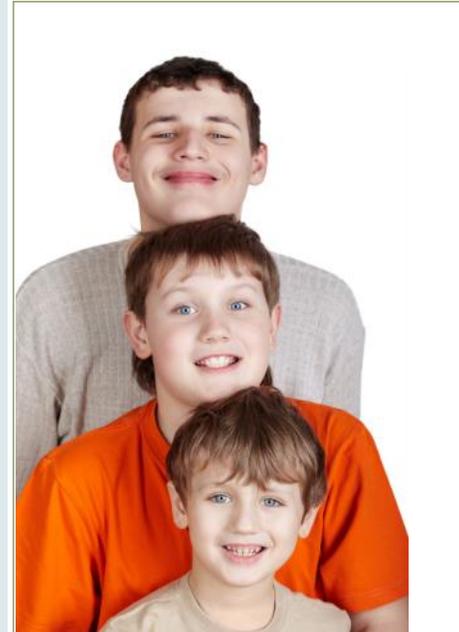
Registry was able to extend its utility beyond its customary use of supporting empirical research studies and assist the State Implementation Grant, a \$900,000 award to UNC researchers by the U.S. Department of Health and Human Services.

The goal of the State Implementation Grant is to improve services in North Carolina for young children with ASD and their families. A key component is a needs assessment of families across the state with respect to their experiences with early screening, diagnostic assessments, and early intervention. The Registry provided a ready resource to identify and contact a racially, ethnically, and geographically diverse group of over 1,000 families with young children to complete the needs assessment. More importantly, it provided more than 400 participating families thus far with a compelling opportunity to share their expertise and positively impact the provision of services in the state.

CIDD Research Participant Registries information is available at:
cidd.unc.edu/registry/autism

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International Meeting for Autism Research 2014

CIDD Director, Joe Piven, MD, and Director of the UNC TEACCH Program, Laura Klinger, PhD, served as Scientific Program co-Chairs of the 2014 International Meeting for Autism Research (IMFAR) recently held in Atlanta.

IMFAR is an annual scientific meeting, convened each spring, to exchange and disseminate new scientific progress among ASD scientists and their trainees from around the world.

"As the scientific investigation of ASD continues to advance at a remarkable pace, IMFAR has become an essential and exciting forum for researchers and clinicians to share findings with each other and the broader autism community," said Francesca Happé, PhD, president of the International Society for Autism Research (INSAR). "It is impossible to attend IMFAR and not be inspired and energized by what we are learning from our colleagues, as well as our stakeholders."

"The research presented at this year's IMFAR is incredibly promising as we are translating scientific discoveries into clinical programs that make a difference in our ability to diagnose and treat autism from infancy to adulthood," said Dr. Klinger.

"For example, we are discussing ways to detect symptoms of autism as early as two months of age and the importance of treating anxiety and depression among adults with ASD. The global reach of this conference, with researchers from Atlanta to Addis Ababa presenting and sharing ideas to better serve individuals with ASD and their families worldwide, is particularly inspiring."

"I can't think of a more dynamic area of scientific endeavor than the field of autism research, which, as this meeting demonstrates, has attracted many of the most impressive scientific minds to the cause of helping people with autism, including some impressive, young researchers," said Dr. Piven. "IMFAR provides a critical opportunity for dialogue and fosters a spirit of collaboration among the full array of scientists focused on ASD research."



Drs. Joe Piven and Laura Klinger

Dr. Mark Zylka Honored with Hettleman Award

Mark Zylka, Ph.D., Associate Professor in Cell Biology and Physiology and the UNC Neuroscience Center, has been awarded the Phillip and Ruth Hettleman Prize for Artistic and Scholarly Achievement by Young Faculty.



Dr. Mark Zylka

Zylka is recognized for his innovative work in two research areas: pain and neurodevelopmental disorders. His nomination letter focused on his identification of a protein that inhibits pain responses in animal models. Based on that discovery, Zylka and his colleagues have developed an injectable therapeutic for those who suffer from chronic pain.

In late August 2013, the prestigious journal *Nature* published Zylka's paper on a class of enzymes that has a profound effect across dozens of genes linked to autism. These findings could illuminate environmental factors behind autism spectrum disorders and contribute to a unified theory of how the disorder develops (go.unc.edu/o3ACy).

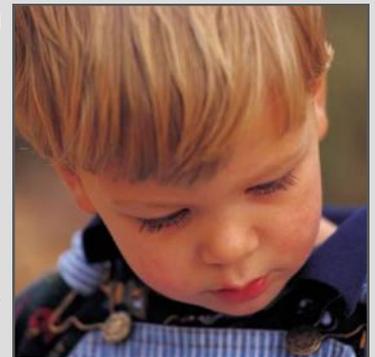
William D. Snider, director of the UNC Neuroscience Center, noted one reason Zylka's work is, "so powerful is that he combines biochemical and pharmacological approaches."

The Hettleman Prize recognizes the achievements of outstanding junior tenure-track faculty or recently tenured faculty. Phillip Hettleman, who was born in 1899 and grew up in Goldsboro, established the award in 1986. He earned a scholarship to UNC, went to New York and in 1938 founded Hettleman & Co., a Wall Street investment firm.

Elevated Repetitive Behaviors at 12 Months Age a Potential 'Red Flag' for Autism

A core feature of autism, 'restricted and repetitive behaviors' range from arm and hand flapping to insistence on a set routine or limited set of interests and activities. Relatively little is known about how these behaviors manifest in infants and toddlers who go on to develop autism.

As part of the NIH funded Infant Brain Imaging Study, Dr. Jason Wolff and colleagues examined how such behaviors unfold early in the lives of young children at-risk for autism. They tracked profiles of restricted and repetitive behaviors in 243 toddlers at low- and high-risk for autism from ages 12 to 24 months using a parent-report measure. They found that all forms of restricted and repetitive behavior were significantly increased in children who developed autism. These differences were evident starting at age 12 months, years before the average age of diagnosis. Children with elevated repetitive behavior at age 12 months were 4 times more likely to show signs of autism by age 2 than children with little or no repetitive behavior.



The authors note that while some amount of such behavior is expected as part of healthy early development, significantly elevated repetitive behaviors at 12 months age may be a 'red flag' for autism, noting also that differences were found using a simple, 5-10 minute parent report. This may suggest that parents are able to detect these behaviors early on, making restricted and repetitive behavior a good potential target for early screening and intervention.

The study, "[Longitudinal patterns of repetitive behavior in toddlers with autism](#)" published in the *Journal of Child Psychology and Psychiatry* (online: 19 FEB 2014), was one of 5 studies featured at the 2014 IMFAR press conference in Atlanta and has been profiled in a number of media publications.

CIDD Welcomes New Psychologist, Lynn Makor



Lynn Makor

Welcome to Lynn Makor, MA, who joined our faculty in April and is serving as the North Carolina Department of Public Instruction (NCDPI) Consultant for School Psychology. In her full-time role as Consultant for School Psychology, Lynn provides technical assistance to school systems, educators and school psychologists across North Carolina. In addition, she works with other DPI staff in the development of policies that affect students with disabilities.

Prior to transitioning into this role, Lynn was in her 14th year of service within Union County Public Schools in Monroe, NC. She served as the district's Co-Lead School Psychologist from 2006-2010, before returning to school-based practice from August 2010 through March 2014. Lynn has had involvement in developing district level policies related to initiatives such as Responsiveness to Instruction (NCRtl) and Positive Behavioral Interventions and Supports (PBIS), as well as the development of procedures for training and utilizing district-level teams in the assessment and diagnosis of Autism Spectrum Disorder.

Lynn also has consultative and training experience on topics such as the intervention process for struggling learners, best practices in assessment and identification of students with disabilities, and the IEP team process specific to special education evaluation and eligibility, based on state/federal guidelines and best practices.

Lynn's reaction to transitioning into this new role is one of excitement, "I am very much looking forward to growing my skill set through the experiences I will gain within this role." She notes that her ultimate goal "is to do the absolute best job that I can to advocate for the needs of children through my advocacy efforts in promoting and enhancing the profession of School Psychology within the state of North Carolina."

Lynn and her husband, Manfred, are in the process of relocating their family to the Raleigh area. They have three children (Marek-4 ½, Lukasz-3, and Katriel-4 months), as well as their dog and two cats.

Please join us in welcoming Lynn! She can be reached at 919-843-7049 or lynn.makor@cidd.unc.edu.

As we welcome Lynn, we would also like to take time to thank Caroline Hexdall, Ph.D. for her years of service in the School Psychology Consultant role and for her time and effort in making Lynn's transition a smooth one!

UNC Research Featured in Top 20 Autism Advances of 2013

The Interagency Autism Coordinating Committee (IACC) has published its selections for the twenty most significant studies in autism research in 2013. The work of Drs. Brian Boyd and Sam Odom on the "Comparative efficacy of LEAP, TEACCH and non-model-specific special education programs for preschoolers with autism spectrum disorders" is featured among the IACC top picks.



Dr. Brian Boyd

In February 2014, Boyd and Odom published findings in the *Journal of Autism and Developmental Disorders* on the efficacy of early intervention school-based treatment programs for children with autism spectrum disorder (ASD). "This is the first study designed to compare long-standing comprehensive treatment models for young children with ASD. The study found that children made gains over the school year regardless of the classroom's use of TEACCH, LEAP or no specific comprehensive treatment model," explains Dr. Boyd, Assistant Professor, Division of Occupational Science and Occupational Therapy in UNC's Department of Allied Health Sciences. "This study may shift the field's thinking about comprehensive treatment models designed for young children with ASD. Perhaps it's not the unique features of the models that most contribute to child gains but the common features of the models that most influence child growth."

The 2013 IACC Summary of Advances includes major advances in understanding the complex causes of autism spectrum disorder (ASD), prevalence and identification of ASD in diverse communities, novel methods for early detection and intervention, and the impact of different services approaches on outcomes for individuals with autism and their families.

"The IACC selected these 20 studies as the most informative and transformative advances of the last year. They offer the possibility of directly improving the lives of those with ASD, and significantly furthering our understanding of autism," said IACC Chair Dr. Thomas Insel. Given the accelerated pace of discovery in the field of autism, these 20 studies represent only a small fraction of over 2,000 published findings in 2013, which address all seven objectives of the [*IACC Strategic Plan for Autism Spectrum Disorder Research*](#). In addition to the 20 selected studies, the *2013 Summary* includes a list of all 94 papers nominated by IACC members.

One of those nominated papers includes research from UNC's Infant Brain Imaging Study (IBIS Network), "White matter microstructure and atypical visual orienting in 7-month-olds at risk for autism" published in the *American Journal of Psychiatry* August 2013. In this study, Dr. Jed Elison showed that 7 month-olds who go on to develop autism show distinct patterns of visual orienting as measured by sophisticated eye tracking equipment. "These are not behaviors that can be observed with the naked eye" Elison states, "yet, they are thought to be important for later social and cognitive development – split-second delays in shifting gaze between important aspects in one's environment, at specific times during development, could have long lasting effects on social development."

Elison and colleagues also showed that a specific part of the brain thought to connect areas that process basic visual information and areas that help move our attention may not be functioning in a typical manner in 7 month-olds who later develop autism. The splenium is part of the largest white matter fiber bundle in the brain, the corpus callosum, and is proving to play an important role in patterns of brain development that lead to autism.



Dr. Jed Elison

"We hope that understanding brain and behavior development during the first year of life will help us develop procedures to enhance early identification of ASD, and perhaps in the not-too-distant-future, develop strategic interventions that could be implemented during a time period of extraordinary plasticity" said Elison, now an assistant professor at the Institute of Child Development, University of Minnesota.

Dr. Jackson Roush Named LEND Director

CIDD is pleased to announce that Jackson Roush, PhD has been named the Director/Principal Investigator of our Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program.



Dr. Jackson Roush

LEND is one of the CIDD's three federally funded core grants (along with the UCEDD and IDDRRC) and is funded through HRSA's Maternal Child Health Bureau. This grant provides core support for in-depth graduate level interdisciplinary training as well as interdisciplinary services and care. Dr. Roush has been the Audiology Section Head at the CIDD for many years and is Professor and Director of the Division of Speech and Hearing Sciences, University of North Carolina School of Medicine. He has many years of teaching and clinical experience, and has directed national training and leadership grants funded by MCHB and OSEP.

Dr. Roush will be assisted in the LEND leadership effort by Dr. Rob Christian, Psychiatrist/Pediatrician, our new LEND Associate Director and Dr. Jean Mankowski, Psychologist, our new LEND Training Director. Dr. Roush takes over the LEND Director position from Dr. Stephen Hooper who directed the LEND program for over a decade and was recently named Chair of the Department of Allied Health Sciences. In addition, our LEND program was co-directed by Dr. Angela Rosenberg who also served as the program's Training Director. Dr. Rosenberg retired from UNC on March 1, 2014.

Please join us in thanking Drs. Hooper and Rosenberg for their years of excellent service and dedication to the LEND program and welcome Drs. Roush, Christian and Mankowski. We are certain that they will continue to lead our LEND program in new and exciting directions!

Dr. Becky Pretzel Reappointed as Act Early Ambassador

Congratulations to Becky Edmondson Pretzel, Ph.D., for being selected to serve another two-year term as Act Early Ambassador for the state of North Carolina!

The Act Early Ambassador project is a collaborative effort on behalf of CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD), the Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau (MCHB), the Association of University Centers on Disabilities (AUCD), and the Association of Maternal and Child Health Programs (AMCHP).

Act Early Ambassadors serve as state liaisons to the "Learn the Signs. Act Early." initiative and work as community champions with programs that serve young children and their parents, such as Head Start and Early Head Start, WIC, home visiting, and health care and child care professionals to improve early identification of autism and other developmental disabilities and collaborate with state agencies and campaign partners to improve policy and programs for early identification.

Becky was one of the first 10 Ambassadors selected 3 years ago and has worked closely with the NC Autism Alliance to enhance and improve early identification efforts. This has included successful grant funding from AMCHP to work with targeted faith-based organizations and also from HRSA for the recent ASD State Implementation Grant. Additionally in this role, Becky continues to provide training and technical assistance to professionals and families who play pivotal roles in monitoring child development and in the early identification process.



Dr. Becky Pretzel

Forensic Psychology Related to Intellectual Disability and the Death Penalty Spotlight on Dr. Greg Olley



Dr. Greg Olley

In 2001, North Carolina became the 21st state to pass a statute prohibiting the death penalty for people with what was then called mental retardation. Six months later, the United States Supreme Court in its *Atkins v. Virginia* opinion, applied this prohibition nationally.

In the 12 years since then, attorneys have requested many “*Atkins* hearings” for their clients accused of or appealing their sentences in capital crimes. In such hearings, experts for the prosecution and the defense are retained to conduct an evaluation of the defendant and to write a report and testify to their findings. Attorneys often seek psychologists or other mental health professionals who have a background in intellectual disability research and clinical service to serve as experts in *Atkins* hearings.

Shortly after the North Carolina statute was passed, Dr. Greg Olley, psychologist at the CIDD, began to serve as an expert in *Atkins* hearings in North Carolina and later in other states. In 2005, the Division on Intellectual and Developmental Disabilities of the American Psychological Association created an *ad hoc* Committee on Intellectual Disability and the Death Penalty and appointed Dr. Olley to chair the committee.

Since that time, Dr. Olley and other members of the committee have testified as experts in *Atkins* hearings in many states, served as consultants in other cases, and written numerous journal articles and book chapters intended to clarify the accepted practices in the diagnosis of intellectual disability. In a further effort to establish standards that courts will recognize, the American Association on Intellectual and Developmental Disabilities will soon publish an edited book on this topic in which Dr. Olley has written three chapters.

The need for clarification of diagnostic methods comes largely from the fact that the *Atkins* opinion left to the states the responsibility to determine state standards for diagnostic procedures. Thus, the standards for diagnosis vary from state to state, and clarification of those standards often comes from court opinions. The testimony of Dr. Olley and members of his committee serves to emphasize the methods of diagnosis that have the strongest basis in research and clinical practice.

For instance, Dr. Olley recently assisted the American Psychological Association in writing an *amicus curie* (friend of the court) brief in the case of *Hall v. Florida*. This case challenges Florida’s statute that does not recognize application of the standard error of measurement in the interpretation of intelligence tests. The APA brief points out the scientific basis for measurement error and its application to IQ scores. The Court will rule on this case in June.

Involvement in *Atkins* cases has led Dr. Olley to related activities. He has represented the APA in an advisory group to the World Health Organization in their terminology for the upcoming ICD-11. He is also a member of the Policy and Positions Committee that is updating policies for the Arc of the United States and the American Association on Intellectual and Developmental Disabilities.

When not engaged in issues of criminal justice and the death penalty, Dr. Olley is the Chairperson of the North Carolina Commission for Mental Health and Substance Abuse Disorders, which writes the rules for statutes that affect people with these disabilities and advises the state Division on Mental Health, Developmental Disabilities, and Substance Abuse Services. He is a Fellow of the American Psychological Association and the American Association on Intellectual and Developmental Disabilities, the husband of Ann Cox, and a proud parent of one son, three grandchildren, and 16 chickens.

International Interdisciplinary Visitors

In addition to providing families with a variety of clinical services (thirteen clinics), the CIDD is a training center for interdisciplinary clinical expertise. This spring, the CIDD hosted visitors from afar to observe clinical operations and meet with the clinical teams.

On March 12, clinicians from the Center for Autism Research at the King Faisal Specialty Hospital in Riyadh, Saudi Arabia observed the School Age Team evaluation at the CIDD. Their visit was arranged by The National Professional Development Center on ASD at FPG, where they spent four weeks receiving training and practice in early intervention.



*Front row from left: Rogaiyah Hamidaddin, speech/language pathologist and Ashwaz Alzamel, special educator
Back row from left: Leslie Payne, social work trainee; Morgan Parlier, social work; Donna Yerby, Special Education; Cara Damiano, psychology intern; Adrienne Villagomez, psychology extern*

The CIDD hosted an interdisciplinary team from KK Women's and Children's Hospital in Singapore April 21-23. Their goals included studying assessment and intervention methods in order to improve service delivery in their setting. The clinicians were briefed and observed the Hearing and Development and School Age Team clinics and met with individual clinicians during the course of their visit.

From left to right: A/P Mary Daniel (Senior Consultant & Head, Clinical Services, Dept of Child Development, KK Women's and Children's Hospital, Singapore); Stephanie Koo (Senior Educational Facilitator, Dept of Child Development, KK Women's and Children's Hospital, Singapore); Zhang Hua (Senior Staff Nurse, Dept of Child Development, KK Women's and Children's Hospital, Singapore); Chih-Ing Lim (Investigator, FPG Child Development Institute, UNC-CH); Mian Yee Choy (Senior Occupational Therapist, Dept of Child Development, KK Women's and Children's Hospital, Singapore)



CIDD Postdoc & Trainee Accomplishments and News

Rebecca Payne Presents at AAIDD Annual Meeting

Rebecca Payne, M.Ed., is a Leadership Education in Neurodevelopmental Disabilities (LEND) fellow at CIDD and a doctoral candidate in Early Childhood, Special Education, and Literacy at UNC. In June of this summer, she will be presenting, in conjunction with Deb Zuver and Emily Kertcher, at the American Association on Intellectual and Developmental Disabilities (AAIDD) Annual Meeting in Orlando, Florida.

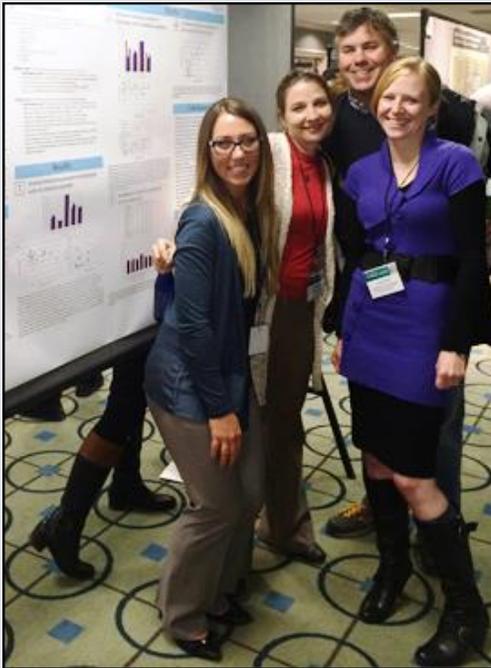
Rebecca's presentation, *Complexity of Transition: Unpacking the Issues and Moving Forward*, reviews the current state of transition planning from an education perspective, investigating the needs of students, families, and professionals. She presents research on how education personnel are trained and examines accessibility needs for families as they experience the transition planning process. The presentation addresses ways to prepare educators and educate families with low literacy skills on transition planning and PSE options.



Rebecca Payne

2014 Gatlinburg Conference

Portia Kunz, Ph.D., and Sheena Berry, B.A., presented preliminary data from their translational research with Rob Christian, M.D. and Anne Wheeler, Ph.D., which investigates the developmental trajectory and factors related to observed anxiety concerns within the Angelman Syndrome population.



From left: Sheena Berry, Anne Wheeler, Rob Christian, and Portia Kunz

Adrienne Villagomez presented data from a national fragile X survey on access and quality of healthcare services for individuals with fragile X syndrome.

Rob Christian, M.D., and Kylee Miller, Ph.D., presented on aggression and self-injurious behaviors in a broad clinical population, in a symposium chaired by Anne Wheeler, Ph.D., regarding aggression and self-injurious behavior in I/DD. In addition, Kylee presented data from her pilot study investigating the relationship between weight status and executive functioning in preschool-aged Portuguese children.



From left: Sheena Berry, Portia Kunz, Rob Christian, Adrienne Villagomez, Kylee Miller, Anne Wheeler

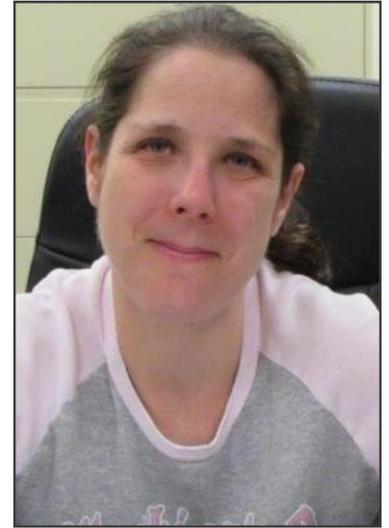
CIDD Postdoc & Trainee Accomplishments and News *continued*

LEND Advocacy Trainee, Alexis Teplin

Congratulations to Alexis Teplin, the CIDD Advocacy trainee for 2013-14 in the LEND (Leadership Education in Neurodevelopmental Disabilities) program at the CIDD. Trainees, selected in a range of disciplines, participate in a problem-based learning (PBL) course and an intensive leadership consortium, as well as research, clinic, and service at the CIDD. Alexis attended Berkshire Community College in Pittsfield, Massachusetts and continued her education in early childhood education at Durham Tech.

Alexis's goals for the past year included learning about supports for children with disabilities, learning problem-solving approaches, and learning how to advocate for herself and others. With support from her education coach, Adrienne Villagomez, Alexis completed the graduate-level PBL course, Developmental Disabilities Across the Lifespan. She presented at two state conferences with her mentors, Deborah Zuver and Donna Yerby, and was a member of the Postsecondary Education Team at CIDD. Alexis plans to continue participation in the NC Postsecondary Education Alliance. She is currently employed in childcare at the Chapel Hill-Carrboro YMCA.

The CIDD implemented the first graduate-level leadership postsecondary education training opportunity in the nation for young adults with developmental disabilities in 2010. The model has elicited national recognition and is now being implemented in LEND programs at other universities.



Alexis Teplin

Community Outreach at the Annual Health Fair/Feria de la Salud



CIDD psychology post doctoral fellow, Lynn Hoffman

Volunteers with the Autism State Implementation Grant distributed materials about early autism screening and diagnosis at the annual Feria de la Salud at St. Thomas More church on March 30. Materials included the CDC's "Learn the Signs. Act Early." booklets and pamphlets in English and Spanish, as well as contacts for additional support services such as TEACCH and Family Support Network.

Dr. Emily Kertcher, Project Coordinator, organized the community outreach effort and was assisted by LEND trainee Fatima Beck, CIDD psych post doc Lynn Hoffman, TEACCH psych post doc Nicole Ginn, and Caroline Irick and Hannah Morse, students from the Division of Occupational Science and Occupational Therapy.

CIDD Together with TEACCH "Light It Up Blue!" for 2014 World Autism Awareness Day



Thank You to Our Epic Super User Team for their dedication to training and helping us adapt our clinical operations to the new system!



Pictured from left: Teresa McCrimmon, Laura Martin, Tom Struchen, Rob Christian, Twyla Peoples, Sheila Fogleman, Tom Gray - not pictured Margaret DeRamus and Morgan Parlier

Your Support

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.

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