

101 Renee Lynne Court Carrboro, NC 27510 Phone: 919-966-5171 Fax: 919-966-2230 www.cidd.unc.edu

#### Issue # 8 August 2011

# Inside the Institute

#### **New Social Skills Clinic**

CIDD faculty Dr. Gabriel Dichter and Dr. Lauren Turner-Brown will be establishing a new social skills clinic at the CIDD, scheduled to begin seeing patients in the Fall of 2011. The group-based clinic is a derivative of a manualized intervention called Social Cognition and Interaction Training for Autism (SCIT-A), developed in collaboration with CIDD Associate Director Dr. James Bodfish and UNC Psychology faculty Dr. David Penn. The clinic will be open to adolescents and adults with a range of high functioning neurodevelopment disorders, and will focus on improving social cognition (i.e., emotion perception, attributional style, and theory of mind) and social functioning, and will also address issues related to independence, transition from school to



work, and establishing healthy social relationships.

The clinic is an example of how the CIDD supports the translation of clinical intervention research into clinical practice. In 2005, Drs. Turner-Brown, Dichter, and Penn adapted an existing group-based intervention previously developed by Dr. Penn for use with a high functioning autism population. They conducted a small pilot

Gabriel Ditcher, PhD. (right) and Lauren Turner-Brown, PhD .

# Newsletter Highlights

New Social Skills Clinic	1, 8
National Core Indicators	1, 8
ASTAR Judges' Science School	2
Self-Advocacy Summit	2
From the Desk of the Director	3, 9
New Funding across the CIDD	4, 5
Recent PhD Defenses	5
Recently Published Papers	6
Accomplishments and Awards	7
Announcements & Support	9, 10

## National Core Indicators Program

Continued on page 8

The CIDD has partnered with the Division of Mental Health, Developmental Disabilities, and Substance Abuse Services (DMHDDSAS) of the NC Department of Health and Human Services for over a decade to implement the National Core Indicators program. National Core Indicators (NCI) was established as a collaborative effort among participating National Association of State Directors of Developmental Disabilities Services and the Human Services Research Institute (HSRI) to support state developmental disabilities authorities in developing and implementing a standard set of performance measures used by states to evaluate and improve services for individuals with developmental disabilities and their families. The National Core Indicators are used by the NC Division of MH/DD/SAS as part of their ongoing quality management efforts.

North Carolina joined the National Core Indicators effort in 1999 and is one of twenty-seven states that currently participate. By providing surveys that measure specific indicators, NCI enables each state to determine the effectiveness of programs serving people with developmental disabilities. The current set of performance indicators includes approximately 100 consumer, family, systemic, cost, and health and safety outcomes – outcomes that are important to understanding the overall health of public developmental disabilities agencies. Associated with each indicator is a source (type of survey) from which the data are collected. Sources of information are comprised of the Consumer survey which includes for example, empowerment and choice issues, and three family surveys which focus on satisfaction with supports.

A University Center for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD) with core funding from the Administration on Developmental Disabilities (ADD A Developmental Disabilities Research Center (DDRC) with core funding from the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) A Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Program with core funding from the Maternal and Child Health Bureau (MCHB)

#### ASTAR National Judges' Science School

The Advanced Science and Technology Adjudication Resource Center (ASTAR) sponsors National Judges' Science Schools with training curriculum focusing on science and technology concepts, research methodologies and terms of reference for five foundation areas of evidence: forensics; neuroscience; genetics; addictive disorders; computer science and information technologies. These Science Schools address the spectrum of science and technology considerations which form the background bulwark of many complex court cases.

ASTAR's most recent Judges' Science School took place at UNC's Friday Center March 16-18 of this year. The program --"Developmental Forensics of Children Adjudicated by Courts" -- was attended by approximately 100 judges from 30 states. The program involved lectures, discussions, and workgroups led by faculty from UNC and also from universities around the country.

Greg Olley, Ph.D., clinical professor and psychologist at the CIDD, Jim Bodfish, Ph.D., professor of psychiatry and pediatrics and Associate Director of the CIDD, and Joe Piven, M.D., professor of psychiatry, pediatrics, and psychology and Director of CIDD were among the featured presenters at this year's ASTAR meeting.

Drs. Piven and Bodfish spoke on "State of the Science: Autism and Other Developmental Disabilities." Their session provided information on the diagnosis, phenomenology and pathogenesis of autism, addressed current issues involved in the controversies regarding autism, as well as current issues involved in the treatment of autism. Dr. Olley presented on "Lessons Learned from Atkins v. Virginia: Implications for Juveniles." The session addressed the risk and protective factors in child development and steps to improve outcomes for juveniles from high risk backgrounds.

In addition, Drs. Piven, Bodfish, and Olley served as "Science Advisors" to groups of judges who met in adjudication workshops during the meeting to produce brief documents for judges on specific topics related to juveniles. These discussions and resulting briefs focused on such topics as: how judges should think about the degree to which an "expert" in autism or other developmental disabilities is really an expert, how judges could interpret the expert reports the court receives, and issues around the causes and standards for treatment of autism and related conditions.

Judges play a pivotal role in a variety of issues affecting individuals with disabilities and their families and CIDD was pleased to be able to support this important effort to help educate judges about current issues and standards of practice in the field of developmental disabilities.

#### Self-Advocacy Summit



North Carolina Developmental Disability Network partners, the Carolina Institute for Developmental Disabilities (UCEDD, LEND & IDDRC), the NC Council on Developmental Disabilities, Disability Rights NC, participated in a regional Self-Advocacy Summit held in Atlanta on March 10 and 11. Sharon Lewis, the Commissioner of the Administration on Developmental Disabilities organized the summit with the purpose to plan steps to strengthen and enhance selfadvocacy efforts at the state level and to make recommendations for actions at the national level. Four more summits will take place across the country. Commissioner Lewis wants to develop national policy leading to a stronger, more effective and long-lasting self-advocacy movement.

**Photo Includes**: NC Team: (left to right) Rusty Bradstock, NC Council on Developmental Disabilities; Holly Riddle, NC Council on Developmental Disabilities;

Beth Stalvey, NC Council on Developmental Disabilities; Vicki Smith, Disability Rights NC; Joan Johnson, Beyond Academics, UNC -G; Ed Crissman, Self-Advocate, Autism Society; Lalenja Harrington, Beyond Academics, UNC-G; William Gadsden, student, Beyond Academics, UNC-G; Steve Jordan, NC Division of Mental Health/Developmental Disabilities/Substance Abuse Services; Deb Zuver, CIDD-UNC; (in front) Eric Chavis, Association of Self-Advocates of NC; Kelly Woodall, Association of Self-Advocates of NC.

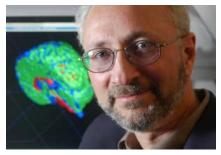
Carolina Institute for Developmental Disabilities <u>www.cidd.unc.edu</u>



In the last issue of the CIDD newsletter I discussed the importance of having comprehensive centers for developmental disabilities. In this issue, I can't help but notice that the articles capture the comprehensive nature of activities at the Carolina Institute and clearly demonstrate the strength of our collective efforts to provide a range of cutting edge services, education and training, and important research.

One of the new words in our modern day research lexicon, translational research, is an important focus of efforts within the CIDD. The lead article in this issue describes efforts by Drs. Gabriel Dichter and Lauren Turner-Brown to launch a new clinical offering, "The Social Skills Clinic'. Building on experience and findings from funded research by Dr. Turner-Brown and Dr. David Penn, in the Department of Psychology, this clinic will focus on improving social function in high IQ individuals with a range of developmental disorders. The goal of this work is to ultimately increase independence by improving the successful interpersonal interactions of individuals with developmental disorders. On the other end of the spectrum of research, in the basic science arena, Drs. Ben Philpot, Mark Zylka and Bryan Roth begin the first steps in moving findings from the basic science laboratory to the clinic to treat individuals with Angelman Syndrome. This study also has potential implications for idiopathic autism and intellectual disabilities more broadly. These researchers recently received a large grant from the Simons Foundation to identify compounds for treatment of abnormalities in mice that are due to the same genetic abnormality seen in individuals with Angelman Syndrome. As one of the 'autisms', Angelman Syndrome is often characterized by the presence of autistic features in addition to the more common presentation of intellectual disability. Study of geneticallydefined subtypes of autism is a critically important strategy for understanding the diverse pathophysiologies that are likely to underlie autistic behavior. In parallel with this effort, Drs Anne Wheeler, Jim Bodfish, Rob Christian and others, have started the first regional Angelman Syndrome Clinic in the U.S. Together, the efforts of these basic science researchers and clinicianscientists to join cutting-edge research with clinical practice epitomize our best efforts for developing effective interventions for individuals affected with these severe neurodevelopmental disorders. Also important to note in this issue is the work of other basic scientists, Dr Patricia Maness and Dr Eva Anton who are conducting pre-clinical research on neuronal development relevant to autism, schizophrenia and other neurodevelopmental disorders that will undoubtedly lead the way to further understanding of the molecular and cellular basis of these conditions. Congratulations to Dr Anton on receiving a prestigious Eureka Award from the NIH.

In a separate domain entirely, our efforts to work closely with our community to ensure best practices for the care and treatment of individuals with developmental disabilities are clearly illustrated by several articles in this issue. In partner-



By Joe Piven, M.D.

ship with the N.C. Division of Mental Health, Developmental Disabilities and Substance Abuse, Drs. Becky Edmonson Pretzel, Debbie Reinhartsen and others oversee a critical aspect of the National Core Indicators project in North Carolina- ensuring the quality of systematic assessment of raters in the field whose efforts ultimately examine the effectiveness of state services for adults with developmental disabilities. In other efforts, contributing to the ability of the judicial system to best serve individuals with developmental disabilities, this spring Drs. Jim Bodfish, Greg Olley and I taught federal judges from all over the U.S.in a two day 'science camp for judges', about problems faced by autistic individuals and those with intellectual disabilities in the courts. And, at the intersection of the worlds of developmental disabilities, community and policy, Deb Zuver and others participated in a summit on self-advocacy for individuals with developmental disabilities that had as its focus strengthening the voices of individuals with developmental disabilities in their communities.

Finally, the range of education and training activities in the Institute are well represented by two recent Ph.D. students working in the area of developmental disabilities in conjunction with faculty and resources at the CIDD. Drs. Kim Carpenter and Jed Elison successfully defended their dissertations in the areas of systems neuroscience and developmental psychology, respectively. They are two of our best and brightest graduates and we are certain they will make important contributions to improving the lives of individuals with developmental disabilities. And in the clinical arena, graduate trainees from the CIDD, funded through the LEND Program and working under the outstanding mentorship of Dr Jack Roush, attended the national Early Hearing Detection and Intervention Conference. Together these trainees, covering the range of activities from neurobiology to developmental psychology to hearing detection and intervention, illustrate the breadth and depth of our training activities in research and clinical practice related to developmental disabilities.

## New Funding Across the Institute

#### NC TraCS Pilot Grant Awarded for Study on Autism in Older Adults

CIDD investigators have been awarded a \$50,000 pilot grant from the NC TraCS Institute to study autism in older adults. Autism Spectrum Disorders (ASDs) are among the most common of the more severe developmental disabilities, yet very little is known about the characteristics of older individuals with ASDs or about the needs of these individuals. The study, "Autism in Older Adults: A Pilot, Descriptive Study" offers promise in furthering our understanding of the characteristics (behavioral, medical, psychiatric, neurological, social) of ASDs in older adults, in providing a basis to develop rational approaches to diagnosis and treatment and to inform policy makers regarding the development of adequate services and other infrastructure (e.g., training the work force; developing nursing home facilities with expertise in ASD) for identifying, assessing and caring for elderly individuals with ASD.

The multidisciplinary team of researchers includes Peggye Dilworth-Anderson, Ph.D., UNC Gillings School of Global Public Health and Director of the Center for Aging and Diversity, UNC Institute on Aging; Mary Lynn Piven, Ph.D., R.N., School of Nursing; Jim Bodfish, Ph.D., Associate Director of the CIDD; and Principal Investigator, Joe Piven, M.D., CIDD Director.

#### New Grant from the U.S. Department of Education will Prepare Audiologists and Speech-Language Pathologists to Work with Deaf and Hard of Hearing Children

A new training grant, co-directed by Dr. Jackson Roush and Dr. Melody Harrison will prepare culturally competent pediatric audiologists and speech-language pathologists for professional roles that enable them to facilitate optimal developmental outcomes for children whose families choose listening and spoken language for their child's communication. The project is based in the Division of Speech and Hearing Sciences, the Department of Allied Health Sciences, and involves collaboration with the Carolina Institute for Developmental Disabilities, The Carolina Children's Communicative Disorders Program, UNC Hospitals, and several statewide agencies. Specific goals are: 1) to recruit and enroll a diverse group of audiology and speech-language pathology students who desire specialization in providing collaborative early identification and assessment/intervention services focused on the development of listening and spoken language skills for infants, toddlers, and school-age children with hearing loss; 2) to provide coursework and field experiences that promote the knowledge and skills needed to deliver collaborative services to families whose children have disabilities in addition to hearing loss, and who may differ with regard to cultural, racial, economic, and linguistic background; 3) to provide clinical experiences in center-, hospital-, school-, and community-based settings where scholars will encounter multicultural populations and where they will be mentored by clinicians who model cultural competence and the development of spoken language through audition; and 4) to create opportunities for students to acquire knowledge and skill in providing outreach and technical assistance to families and professionals in rural and underserved areas. The project will partner with CIDD through trainee participation in outpatient audiology assessments provided by the Hearing and Development Clinic and School-Age Teams. CIDD also hosts Audiology Grand Rounds and provides the venue for leadership workshops provided through the Maternal and Child Health Leadership Consortium.

#### UNC Researchers Awarded Prestigious Grant for Research in Autism Spectrum Disorders

Drs. Ben Philpot (far right in photo), Mark Zylka (middle), and Bryan Roth (left) have been awarded a \$1,050,000 grant from the Simons Foundation to identify drug-like compounds for the treatment of autism spectrum disorders. The three-year grant includes work with an animal model of Angelman syndrome, a neurodevelopmental disorder caused by inactivation of the Ube3a gene. Most cases of autism spectrum disorder are caused by



defects in multiple genes, making the disorder particularly difficult to treat. In contrast, the loss of a single gene, UBE<sub>3</sub>A, causes a severe intellectual disability, Angelman syndrome, an autism spectrum disorder. Some forms of autism may also be caused by chromosomal duplications involving UBE<sub>3</sub>A.

Continued on page 5

## Recent Ph.D. Defenses

#### Kimberly Carpenter, Ph.D. in Neurobiology



Kim Carpenter recently defended her dissertation, "Functional Neuroimaging of the Interaction between Social and Executive Neural Circuitry in Individuals with High-Functioning Autism." Her dissertation research focused on investigating how the brain of individuals with autism integrates cognitive and social information. Specifically, her study provided insight into the neural underpinnings of how individuals with autism complete a cognitive task while inhibiting interference from competing task-irrelevant social information. Dr. Carpenter has accepted a postdoctoral research position under the mentorship of Dr. Helen Egger in the Developmental Epidemiology program at Duke Universi-

ty. Her postdoctoral research will utilize functional neuroimaging to investigate the neural underpinnings of pediatric anxiety disorder.

#### Jed T. Elison, Ph.D. in Developmental Psychology



Jed Elison recently defended his dissertation, "Orienting to Object Exploration in Infancy: Examining the Genetic Liability of Autism." In this study, he found that a proportion of infants who have an older sibling with autism attend to and explore objects in a manner that differs from infants who have a typically developing older sibling, potentially identifying an early diagnostic feature of the disorder. Dr. Elison's primary research interests relate to typical and atypical infant behavior, cognition, and brain development. This summer he will begin postdoctoral training in social-cognitive neuroscience at Caltech with Ralph Adolphs, but will continue to contribute to several research projects at UNC/CIDD including the IBIS project directed by Dr. Joe Piven.

## New Funding Across the Institute continued

Drs. Philpot, Zylka and Roth are affiliated with the CIDD, UNC Neuroscience Center, the Department of Cell and Molecular Physiology (Philpot, Zylka) and the Department of Pharmacology (Roth).

#### Grant Awarded to Purchase Equipment for the Developmental Neuroimaging Core

Dr. Aysenil Belger, Director of the Developmental Neuroimaging Laboratory and Professor of Psychiatry and Psychology, has been awarded a \$36,500 grant from UNC Medical School. The grant is being used to purchase functional near infrared spectroscopy to be used in the Neuroimaging Lab. Functional near infrared spectroscopy (fNIR) is a wearable neuroimaging device (see photo) that enables the continuous, non-invasive, and portable monitoring of changes in blood oxygenation and blood volume related to human brain function. fNIR technology uses specific wavelengths of light, irradiated through the scalp, to enable the noninvasive measurement of changes in the relative ratios of deoxygenated hemoglobin (deoxy-Hb) and oxygenated hemoglobin (oxy-Hb) during brain activity (much like fMRI). These qualities make fNIR suitable for the study of hemodynamic changes due to cognitive and emotional brain activity under many conditions without the drawbacks of fMRI. The new equipment will be used to assess brain functions like attention, memory, planning and problem-solving in typically developing children and in children in which these functions develop atypically.





#### **Two Recently Published Papers**

Scientists in Dr. Patricia Maness' lab report that a gene, the Neuron/Glia-related Cell Adhesion Molecule or "NrCAM", may play a role in autism-related sensory and social deficits. In the study -- <u>NrCAM Deletion Causes Topographic</u> <u>Mistargeting of Thalamocortical Axons to the Visual Cor-</u> <u>tex and Disrupts Visual Acuity --</u> recently published in the *Journal of Neuroscience*, scientists were able to "knockout" the NrCAM gene in mice and found that the absence of the NrCAM gene caused groups of somatosensory and motor thalamocortical neurons to incorrectly connect with the visual cortex resulting in the development of abnormal visual cortical responses.

Since social deficits and resistance to change are common features in ASDs, the NrCAM knock-out mice were also observed interacting with other mice, and were tested for

their ability to "change the rules" in a classic test in animal learning called reversal learning. NrCAM knockout mice displayed impaired sociability, as indicated by avoidance of stranger mice. Although the NrCAM knockout mice were able to learn to find a hidden pedestal in a water maze task, they were impaired after the "rule



change"—a sign of behavioral rigidity in these animals.

"The ability to process sensory information through vision, touch, and hearing has long been noted to be compromised in people with autism spectrum disorders (ASDs). Some individuals are overly sensitive to certain types of sensory information whereas others may have difficulty integrating information from different modalities," explains Dr. Maness, Principal Investigator of the study and Professor in the Department of Biochemistry and Biophysics. "The exact neural circuits that are dysfunctional that could contribute to these difficulties remain obscure. Neurons from sensory organs such as eyes, skin, and ears, and muscles send information from the environment to a relay center of the brain called the thalamus, where sensory and motor thalamic nuclei are located. Thalamocortical neurons in each of these nuclei transfer partly processed information to final destinations in distinct regions of the cerebral cortex (visual, somatosensory, auditory, and motor areas) to process the information in greater detail.

Continued on page 9

Researchers in Dr. Ben Philpot's lab have discovered a new role for a class of receptors that underlie learning and memory processes in the brain. In the study, <u>NR3A-</u> <u>containing NMDARs promote neurotransmitter release</u> <u>and spike timing-dependent plasticity</u>, recently published in the journal *Nature Neuroscience*, they found a unique subtype of these receptors, the NR3A-containing NMDA receptors, is expressed at high levels during formative periods of early brain development. These receptors can promote the release of brain neurotransmitters, but with certain types of brain activity, these receptors can also paradoxically weaken connections between neurons in the brain via processes believed to underlie memory.

Interestingly, it appears that NR<sub>3</sub>A only performs these functions early in development, at a time when information

is first sculpting the brain's architecture. Since NMDA receptor dysfunction has been implicated in a large number of neurological disorders – including schizophrenia, forms of mental retardation, epilepsy, and Alzheimer's disease – these findings may further the understanding of the etiology of these disease states and lead to improved future therapies.



"Before this study, scientists knew that NMDA receptors could be localized near the part of a neuron that releases a chemical signal, but we did not know what the molecular puzzle piece was that made these receptors function differently. It turned out that one of the most understudied components of the NMDA receptor, the NR<sub>3</sub>A subunit, was the missing puzzle piece. NR<sub>3</sub>A receptor subtypes have peculiar functions which allow it to fulfill a number of unexpected functions," said lead study author Rylan Larsen, a graduate student at UNC School of Medicine's Department of Cell and Molecular Physiology.

Study co-authors from Dr. Philpot's laboratory include Rebekah Corlew, Maile Henson, and Adam Roberts. The study was also performed in close collaboration with Dr. Richard Weinberg in UNC's Department of Cell and Developmental Biology, as well as with collaborators Masayoshi Mishina, Masahiko Watanabe, Stuart Lipton, Nobuki Nakanishi, and Isabel Pérez-Otaño.

#### **CIDD Trainees and Faculty Participate in National EHDI Conference**

Students from UNC's graduate programs in audiology and speech-language pathology participated in the national Early Hearing Detection and Intervention (EHDI) conference in Atlanta, GA, February 20-22, 2011. The national EHDI conference, which celebrated its tenth anniversary, is cosponsored by the US Maternal and Child Health Bureau, the Centers for Disease Control and Prevention, the American Academy of Pediatrics, and the National Center for Hearing Assessment and Management. The ten UNC students, funded by LEND and



MCH Leadership grants based at CIDD under the direction of Jackson Roush, PhD, joined their counterparts from ten other universities with similar grants to expand personnel with expertise in identification and management of hearing loss in children (group photo). Presentations included LEND projects by UNC students Kate Bowman on hearing screening in the neonatal intensive care unit, and Brittany Richardson comparing diagnostic audiology procedures based on the auditory brainstem response.

#### Ditcher honored with Vanderbilt Award

CIDD Investigator, Gabriel Dichter, PhD, has been awarded the 2011 Vanderbilt University Randolph Blake Early Career Award for the Psychological Sciences.

Dr. Dichter received his PhD from Vanderbilt University in 2004 where he trained with Andrew J. Tomarken, PhD, studying the use of psychophysiology markers, including resting state EEG and affective modulation of the startle eyeblink response, as indicators of risk and treatment response for mood disorders.



Since coming to UNC, Dr. Dichter has applied these techniques as well as functional magnetic resonance imaging (fMRI) to study cognitive and affective processes in mood disorders and autism. Dr. Dichter currently holds a career development award from NIMH to use fMRI to study the neurobiological mechanisms of action of treatments for autism. This research is mentored by CIDD Associate Director, Dr. James W. Bodfish.

#### NIH Eureka grant awarded to UNC neuroscientist Eva Anton

UNC neuroscientist Eva S. Anton, PhD, professor of cell and molecular physiology and CIDD investigator, has been awarded \$1.18 million over 4-years from an NIH program called EUREKA (Exceptional, Unconventional Research Enabling Knowledge Acceleration).

The grant from the National Institute of Mental Health (NIMH) is part of a NIH program that supports exceptionally innovative research projects and enables scientists to test novel concepts, tools and approaches that could have a broad impact on biomedical research. Anton was awarded the grant for his research in the mapping of neuronal placement in the developing cerebral cortex. This project is aimed at defining the neuronal blueprint that forms the brain connectome, a comprehensive map of neural connections in the brain.

With the new grant, Anton said he will "also develop new in-vivo embryonic brain imaging methods that may help us better understand some of the brain developmental abnormalities underlying a spectrum of neurodevelopmental disorders, including schizophrenia and autism spectrum disorders."

#### NC and the National Core Indicators continued

In addition, since joining NCI, the CIDD National Core Indicators team and the Division staff have partnered with Dr. Karen Luken at the NC Office on Disability and Health (NCODH). This collaboration has led to three primary outcomes: (1) the inclusion of specific and timely health-related questions as part of the Consumer Survey, several of which have been adopted by HSRI for the national version; (2) examination of health-related data gathered from the NC Behavioral Risk Factor Surveillance System (NC BRFSS) and National Core Indicators, thus allowing comparison among persons with disabilities, persons without disabilities and persons with DD receiving state supported services; and (3) the establishment of a surveillance workgroup focusing on state efforts related to the health/healthcare of persons with developmental disabilities. This collaboration has allowed the workgroup to target specific areas of concern, such as sedentary lifestyle, obesity, mammogra-



Rebecca Edmondson-Pretzel, PhD.

phy screening and dental care, and to begin disseminating this information.

The NCI Consumer survey consists of a face-to-face interview with an adult who has intellectual deficit and receives at least one service through the Division of MH/DD/SAS (DMHDDSAS). Interviewers are trained throughout the state on the survey process; approximately 800 interviews are conducted per year. In addition, the CIDD assists the state in distributing over 3600 family surveys. These are sent to families who have children who receive services, and families of adults who live at home and those who live in other settings. The data collected will be used to improve practice at the state level and to add knowledge to the field, to influence state and national policy and to inform strategic planning initiatives for the National Association of State Directors of Developmental Disabilities Services.

Dr. Maria E. Fernandez and Ms. Terrie Qadura jointly manage the project at the DMHDDSAS level while Mr. Adolph Simmons, MS, provides oversight over the entire project. Dr. Fernandez, Ms Qadura, and Mr. Simmons work with the Quality Management Team of the Community Policy Management Section, DMHDDSAS. The QM team analyzes NCI data and provides reports to the Division and Local Management Entities on their performance on core indicators as part of the QM/QI initiatives of the public service delivery system at the state and local level. In addition, each mailed survey has a "Comments" page that asks respondents not only to write their perceptions or complaints about the system, but also asks them whether they would like a Division staff member to call them about their services and supports. Survey participants who respond positively are then called by staff members from the Consumer Rights and Advocacy Section of the Division. Many have been pleasantly surprised by the calls that they have received as a result of their participation in the survey. The comments and the calls have enabled the Division to provide immediate action on critical issues.

The CIDD team working on this project includes Principal Investigators, Drs. Debbie Reinhartsen and Rebecca Edmondson Pretzel, as well as Rebecca Greenleaf Bailey, MPH; Kristine Kelsey, Ph.D.; Tom Castelloe, MBA; and Ms. Teresa Buckner. To learn more contact any of the CIDD team members at 919-966-5171 or Dr. Maria Fernandez at the DMHDDSAS 919-733-0696.

#### New Social Skills Clinic continued

study demonstrating feasibility, patient satisfaction, and clinical benefits. Results of this pilot study were ultimately reported in the Journal of Autism and Developmental Disorders and led to pilot funding from Autism Speaks to further develop and refine the intervention. They have subsequently evaluated and modified the intervention and have established a protocol for use in neurodevelopment disorders. The SCIT-A manual has been disseminated to clinics throughout the country and continues to be refined in response to feedback from expert clinicians, therapists, and patients.

Drs. Dichter and Turner-Brown hope that the clinic will fill a clinical need in the community as well as provide a venue for graduate and medical students to receive training in group-based cognitive behavioral intervention for individuals with neurodevelopmental disorders.

To learn more about the social skills treatment clinic contact Dr. Gabriel Dichter at dichter@med.unc.edu or Dr. Lauren Turner-Brown at lauren.brown@cidd.unc.edu.

**Carolina Institute for Developmental Disabilities** www.cidd.unc.edu

#### Fragile X Discussion Group

This spring, the CIDD established a discussion group of researchers who are interested in fragile X syndrome, the most common inherited form of intellectual disability. Many CIDD researchers as well as colleagues in other units at UNC and the Triangle have studied various aspects of fragile X syndrome for several years. The purpose of the group, led by Don Bailey (former director of UNC's Frank Porter Graham Child Development Institute, now a Distinguished Fellow at RTI International) is to share findings, read and discuss recent publications, hear from other experts about their work on fragile X, and consider future interdisciplinary initiatives. The previous meeting on June 27th featured a talk by Dr. Steve Warren, former director of the Schiefelbush Institute for Lifespan Studies and now Vice-Provost for Research at the University of Kansas. Dr. Warren discussed his research on maternal responsivity in fragile X syndrome, with some exciting longitudinal findings. The next meeting will be held from 3:30– 5:00pm on September 12th. Anyone interested in joining the group, which meets approximately every two months, should contact Don at <u>dbailey(arti.org</u>.

#### Director's Column continued

The services, research and training efforts by those portrayed in these articles represent only a portion of the activities of the Institute. While there is not space to mention all of the examples in this issue, clearly even in these tough economic times and strange 100 degree days, faculty, students and staff at the CIDD are finding ways to make important strides towards our achieving our mission -- to positively impact the quality of life for individuals with developmental disabilities and their families in North Carolina by promoting research, training and service.

## **NICHD** Cognition Vision Workshop

Several CIDD faculty including Drs. Joe Piven, Ben Philpot, Brian Boyd, Gabriel Ditcher, and Geri Dawson attended a recent NICHD Cognition Vision Workshop. This workshop co-chaired by Dr. Piven is one of nine workshops sponsored by the NICHD in order to identify the most promising scientific opportunities of the next decade. Learn more.

## **Recently Published Papers continued**

Understanding these circuits and how different genes guide their appropriate development is essential to solving the puzzle of sensory processing differences in autism."

These results in an animal model provide evidence that NrCAM is involved in functions relevant to autism related behaviors. Because visual processing and thalamocortical deficits occur in ASDs, disruption of visual circuitry might contribute to ASD-related deficits such as eye gaze and interpretation of facial expressions, which influence social interactions.

Dr. Galina Demyanenko, Research Professor in Dr. Maness's laboratory, was a lead contributor to the research. The team also collaborated with Dr. Sheryl Moy, Associate Professor in the Department of Psychiatry at UNC, who serves as Director of the Mouse Behavioral Phenotyping Laboratory, a core facility of the Carolina Institute for Developmental Disabilities. Collaborators on visual cortical function include Dr. Benjamin Philpot, Associated Professor in the Department of Cell and Molecular Physiology at UNC and Graduate Student Thorfinn Riday. Funding provided by a research grant from Autism Speaks is gratefully acknowledged.

## Announcements:

Kira Fisher, self-advocate and coordinator of a recent youthfocused self-advocacy training project, has successfully completed the LEND training program for the 2010-2011 academic year. This is the first postsecondary education program at the graduate level to pilot inclusion of a student with an intellectual or developmental disability. Ms.Fisher wrote about her initial experiences as a graduate student with a disability in the LEND program in an



article that was recently published in IMPACT. <u>Click here</u> to read the article. She is working on a follow up article reflecting on her participation in this leadership training opportunity.

NICHD Director, Dr. <u>Alan Guttmacher</u>, visited the CIDD in April. Guttmacher met with CIDD leadership, research investigators, and UNC School of Medicine Dean Roper to discuss the CIDD's ground breaking research initiatives in developmental disabilities. He heard research presentations from Drs. Jim Bodfish (linking clinical observation studies to mouse behavior studies and human imaging), Ben Philpot (linking basic neuroscience findings in a mouse model of a human neurodevelopmental disorder with the search for pharmacotherapeutic agents); and Rob Christian (linking comprehensive centers for developmental disabilities with community service and research).



International radio show, <u>Adults on the Autism Spectrum; TODAY!</u>, interviewed Greg Olley about his work in forensic psychology. <u>Click here</u> to listen to the broadcast which focuses on Dr. Olley's involvement with individuals with intellectual disabilities as they engage the legal system.

 Portia McCoy, a CIDD postdoctoral fellow in Ben Philpot's lab, recently received a fellowship from the Autism Science Foundation to examine the role of Ube3a, a gene linked to Angelman syndrome and autism, in a project entitled "Ube3a Requirements for Structural Plasticity of Synapse." <u>Click here</u> to learn more.



Two undergraduate research assistants in CIDD investigator, Gabriel Ditcher's lab have received UNC Summer Undergraduate Research Fellowships (SURFs) to continue their work on autism studies that they initiated as undergraduate research assistants. Joey Aloi is working with UNC Clinical Psychology graduate student Cara Damiano on a behavioral study of reward processing in autism, and Dillon Cockrell is working with UNC Developmental Psychology graduate student Anna Sabatino on a psychophysiological study of responses to affective stimuli in autism. Both students plan to use data collected this summer for their honors thesis next year.

#### Send us your comments:

We would love to hear from you if you have comments about our newsletter, or if you would like to be added to our newsletter list! A text only version of the newsletter in Word is available. Drop us a line: <u>info@cidd.unc.edu</u>.

Many thanks to our newsletter article writers and editors: Joe Piven, Keath Low, and Julia Tarr

# Carolina Institute for Developmental Disabilities <u>www.cidd.unc.edu</u>

## Your Support

For more than 40 years, the programs of the Carolina Institute for Developmental Disabilities have provided innovative, high -quality clinical, research, and training activities supporting individuals with developmental disabilities.

The population of our state and nation is growing, and the disability community is growing as well. Children are being diagnosed with developmental disabilities such as autism at an exponential rate. Often, families dealing with a loved one with a disability can feel overwhelmed and need a place to find real answers. Through innovative research that improves practice and enhances education, we will find solutions.

Now, more than ever, we need welltrained 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 Medical Foundation of North Carolina's gifting page and choose "Carolina Institute for Developmental Disabilities:" <u>Click Here.</u>

To make a cash donation, please send your check to: The Carolina Institute for Developmental Disabilities, University of North Carolina at Chapel Hill CB# 7255, Chapel Hill, NC 27599-3366.

Contact: Julia Tarr at (919) 966-7519 or julia.tarr@cidd.unc.edu to discuss your giving options.