



Inside the Institute

New NIMH Grant Awarded to CIDD Investigator to Better Understand Emotions in Autism Spectrum Disorders (ASDs)

CIDD Investigator Dr. Gabriel Dichter has been awarded a grant from the National Institute of Health to use psychophysiology to better understand how children with ASDs process emotions. The study is a collaboration with UNC CDL Director Dr. Jim Bodfish and with Dr. Stephen Benning at Vanderbilt University and was funded via President Obama's American Recovery and Reinvestment Act (ARRA) of 2009. The study will use psychophysiology to understand responses to a range of emotions in ASDs. Psychophysiology is the branch of psychology research that uses small sensors affixed to the skin to record physiological processes that occur during psychological states. The study will record minute and imperceptible movements in facial muscles via electromyography (EMG) while children with and without ASDs view standard emotional images as well as images relevant to the core symptoms of ASD.

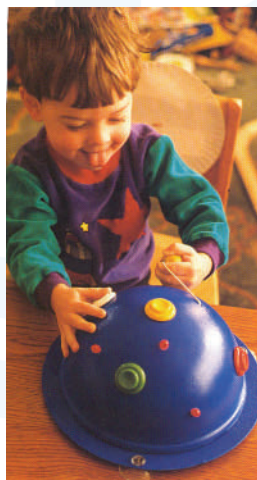


[Click here](#) to watch a video about the study.

Continued on page 5

Early Childhood LINK Program

The Center for Development and Learning's LINK program provides interdisciplinary training and consultation to interdisciplinary teams working within the early intervention and public school systems in North Carolina. The LINK team – Becky Pretzel, PhD, Debbie Reinhartsen, PhD, CCC-SLP, Hal Shigley, PhD, and Sue Porr, MS, MEd, OTR/L - focuses primarily on assessment of and intervention with children who have complex and low incidence disabilities. The disciplines on the team include psychology, speech and language pathology, and occupational therapy. Currently, LINK is partnering with the Department of Public Instruction (DPI) on two ongoing projects – the AAC/AT Initiative and the Preschool Assessment Center Initiative.



Continued on page 5

Newsletter Highlights

CDL Training Program New Course	2
Expansion of the Registry Core	2
From the Desk of the Director	3
Jim Bodfish appointed to NC Council	5
Announcements and Your Support	6

At the Carolina Institute for Developmental Disabilities, we support individuals with disabilities and their families by:

- Identifying and applying innovative solutions to complex issues using an interdisciplinary approach
- Studying best practices and translating research into practical applications
- Promoting self-advocacy, leadership, and inclusion by and for individuals with disabilities
- Training world-class leaders and experts in the field of developmental disabilities

CDL Training Program Adds New Graduate Level Course

This fall the Center for Development and Learning (CDL) in collaboration with UNC's Department of Allied Health Sciences began offering the graduate level course, *Developmental Disabilities Across the Lifespan – An Interdisciplinary Approach*. This course is offered as a required "Problem Based Learning (PBL)" course in the Leadership Education in Neurodevelopmental Disorders (LEND) training curriculum and as an elective course for a limited number of additional students interested in interdisciplinary education in the field of developmental disabilities.

The focus of this course is on preparing interdisciplinary graduate students to acquire advanced knowledge of developmental disabilities and prepare them as evidence-based clinicians, advocates, leaders, and change-agents relative to contemporary practice issues in the developmental disabilities arena. Angela Rosenberg, DrPH, PT, Associate Professor in the Division of Physical Therapy and CDL Director of Leadership Training, is the lead instructor assisted by Occupational Science doctoral student, Emily Furgang, MOT, OTR/L.

The course is uniquely designed to engage groups of students in a faculty mentored, client-centered, problem based style of learning. Actual systems-level and clinical case scenarios provided by CDL faculty, clinicians, researchers, educators and community part-

Continued page 4



Expansion of the Research Participant Registry Core

The University of North Carolina Research Participant Registry Core, one of several cores available to assist Neurodevelopmental Disorders Research Center investigators, maintains databases of individuals and families to help research studies recruit participants. The Registry Core, which includes the Fragile X Registry (FXS), Autism Spectrum Disorders Registry, and Child Development Registry, provides an organized and confidential way to identify and contact potential participants who may be eligible for particular studies. The UNC FXS Registry has 330 individuals from across the United States enrolled. The Autism Registry has more than 5,000 members from North Carolina and the Child Development Registry has over 2,000 infants and siblings from central NC enrolled.

Neurodevelopmental disorders such as autism, Down syndrome, and fragile X syndrome can take a heavy toll on individuals, families, and society. Recent scientific discoveries and research on promising pharmacological and psychosocial therapies provide hope to these families. The pace of this research, however, has been hindered by the difficulty of recruiting the large numbers of participants required for studies of efficacy and comparative effectiveness. One of the best ways to deal with this challenge is to develop a national registry of individuals with neurodevelopmental disorders.

In a joint project with the University of Wisconsin-Madison Waisman

Center's Research Participation Core and UNC's Research Participant Registry Core, the first step to this expansion has already been taken – the development of a single registry of individuals with fragile X associated disorders. UNC and University of Wisconsin are long-standing members of the network of Intellectual and Developmental Disabilities Research Centers, funded by the National Institute of Child Health and Human Development (NICHD). The joint registry project was funded by a supplemental award from the NICHD.

The Collaborative Fragile X Associated Disorders Registry will provide investigators at both research centers access to a larger and more diverse sample than would be possible if the recruitment cores operated independently. This joint venture has accelerated the pace of recruitment into the currently funded projects of both research centers and will further encourage the development of new projects.

The Registries provide a unique opportunity for families and scientists to work together to improve the lives of individuals affected by neurodevelopmental disorders. If you would like to learn more about the Research Participant Registry Core contact Registry Coordinator, Renee Clark rdclark@email.unc.edu; Core Director, Dr. Steve Reznick reznick@email.unc.edu; or telephone toll-free 866-744-7879.



From the Desk of the Director

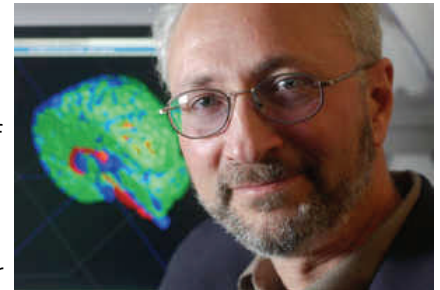
Towards Defining a National Research Agenda on Aging in Autism

It is now widely accepted that autism, originally described as a disorder of infancy by Leo Kanner, is typically a life long condition. However, the overwhelming bulk of research on autism has focused on childhood and adolescence. A significantly smaller portion of studies have focused on adults with only a handful of papers even including subjects over age 50 years. Virtually no research has been published on elderly individuals with autism (> 65 years of age). Nothing is known about the effects of aging beyond age 50, on the biological, psychological and social aspects of autism; or the need for services in this population.

The effects of autism are a significant burden to individuals, families and communities. According to the U.S. census estimates, the elderly population (> 65 years) will more than double in the U.S. between 2000 and 2030, growing to over 70 million. Elderly individuals have an increase in chronic health problems and disabilities with a resulting increasing need for support services. With the current estimate of 1/150 school-age children having an autism spectrum disorder, the numbers of elderly individuals with autism will be a significant public health concern. There is a critical need for research on the effects of aging in individuals with autism.

Numerous examples exist that suggest issues in elderly individuals with autism are likely to differ from those in the general population. Sensory deficits are often an associated feature of autism. Sensory changes are also a hallmark of the aging process. Does the trajectory of sensory changes in autism differ from the general population and if so, what are the implications of this for function and treatment? Mutations in the PTEN gene are known to be associated with autism in rare cases. PTEN is also known to play a role in tumorigenesis. Are individuals with autism at increased risk for some cancers? Individuals with Fragile X Syndrome often meet criteria for autism. The fragile X permutation has been shown to be associated with a neurodegenerative syndrome (FXTAS), presenting with tremor and ataxia, in previously unaffected males (typically grandfathers of probands) over 50 years of age. Are similar degenerative neurological changes present in a subset of individuals with autism? Social support and care of individuals with autism often involves considerable efforts on the part of families. How does this change in older individuals with autism where par-

ents are often no longer available to provide this support? With the aging of the U.S. population, the role and cost of nursing home care has become a major public health issue. How will nursing home care differ for individuals with autism and other developmental disabilities from those who do not have these conditions?



These and other questions will be discussed in a two day workshop organized by the Carolina Institute, in conjunction with the NIMH and researchers at Johns Hopkins. Approximately 30 experts from around the U.S., from multiple disciplines in the fields of autism and aging, will gather in Chapel Hill in March 2010 to begin developing a proposal for a national agenda for research on aging and autism – characterizing the state of the science, identifying current gaps and future directions for research, considering existing resources that could be leveraged to facilitate research and identifying potential research partnerships. Specific topic areas for discussion will include: (I) Epidemiology, Diagnosis and Functional Trajectories; (II) Long Term Care; (III) Health Care Policy/Training; (IV) Neurobiology, and (V) Associated Medical/Psychiatric Factors and Sequelae.

This workshop highlights the strength of the Carolina Institute in bringing together interdisciplinary experts to address an issue of national significance in the field of developmental disabilities. Bringing together novel ideas and state-of-the-art science, this effort will hopefully serve as an example of how we can serve as a platform for effecting changes in research policy on a broader scale – and hopefully demonstrate how the whole of our Institute is clearly greater than the sum of our individual contributions.

The workshop is generously supported by the Ireland Family Foundation. Those interested in reading more about this topic are referred to an excellent paper by Tyler and Noritz in *Clinical Geriatrics* (2009).

By Joe Piven, M.D.

Jim Bodfish Appointed to the North Carolina Council on Developmental Disabilities

Jim Bodfish, PhD, Director of the Center for Development and Learning, has been appointed by Governor Beverly Perdue to serve on the North Carolina Council on Developmental Disabilities (NCCDD). NCCDD works to ensure that people with developmental disabilities and their families participate in the design and have access to appropriate services and supports, as well as other assistance and opportunities which promote inclusive communities. Dr. Bodfish will be working with other Council members to direct funding and research to key policy areas, including health care, housing, transportation, employment, and quality assurance.



Begun in 1962, the NCCDD has a long history of speaking up for the concerns, direction, and policies applying to individuals with developmental disabilities. Council activities are guided by the federal mandate to “promote self-determination, independence, productivity and integration and inclusion in all facets of community life” for people with developmental disabilities and their families. The Council also works to promote a community service delivery system that is personalized to meet the unique needs of each individual with a developmental disability through funding diverse grantees.

“The Council on Developmental Disabilities is pleased to have Dr. Bodfish appointed to the Council,” says Holly Riddle, JD, MEd, Executive Director of the NCCDD. “Dr. Bodfish has spent many years working hands on with people with disabilities. He is a nationally known researcher in the field and his research is strongly rooted in a desire to improve the quality of life for all people with intellectual and developmental disabilities. Dr. Bodfish brings a depth of knowledge and experience that will assist the Council in advancing policies and practices that are evidence based and that promote quality of life for the individuals and families we represent.”

The NCCDD is a 34-member, governor appointed body which represents all of North Carolina. 60 percent of its members are people with developmental disabilities or family members of people with disabilities. The remaining 40 percent are representatives of state and local agencies, policy makers, and legislatures. The Council works closely with the North Carolina Department of Health and Human Services to which it serves as an advisory body under state and federal law.

New CDL Course continued

ners are discussed within the class with questions designed to facilitate active learning regarding the full scope of the service system for individuals with developmental disabilities. Through investigation of these case scenarios students learn key aspects of the field in vast content areas related to developmental disabilities including clinical, policy, community based and individual issues.



The course is offered in both the fall and spring semesters. The fall semester of *Developmental Disabilities Across the Lifespan (PHYT 862)* primarily focuses on cases and challenges related to direct care services including clinical screening, assessment, intervention plans, and clinical outcomes. *Developmental Disabilities Across the Lifespan (PHYT 864)* spring semester will expand this focus to include topics related to population services and health system infrastructure including public policy and advocacy challenges related to individuals with developmental disabilities and their families.

For more information about *Developmental Disabilities Across the Lifespan* contact LEND Training Coordinator, Lorraine Dorsett at lorraine.dorsett@cdl.unc.edu or (919) 966-4788.

New NIMH Grant to Better Understand Emotions in Autism Spectrum Disorders (ASDs) continued

Leo Kanner's seminal paper that first described autism in 1943 was entitled "Autistic disturbances of *affective* contact." Clinically, children and adults with autism have minimal affective response to social aspects of their environment yet can exhibit extreme affective responses to ostensibly inconsequential nonsocial aspects of the environment. This range of seemingly out-of-sync reactions can be exceedingly troubling to parents, can lead to avoidance by peers, and likely detracts from a child's ability to learn naturally from his social environment. Thus, the primary core features of autism may be conceptualized in relation to atypical affective regulation.



Dr. Gabriel Dichter

Dr. Dichter hopes that understanding basic emotional processes in autism will shed light on the neurobiological basis of autism symptoms and may elucidate potential benchmarks of treatment response in autism.



Early Childhood LINK Program continued

The AAC/AT Interdisciplinary Assessment Team Initiative works to establish a network of public school-based teams that have the capacity and capabilities to effectively assess children with moderate to severe communication difficulties and determine their need for an alternative or augmentative communication system or device. With contractual support from DPI, the LINK team currently provides annual workshops, consultation and technical assistance to regionally-based interdisciplinary teams across the state.



The Preschool Assessment Center Initiative selects and trains regionally based interdisciplinary preschool assessment teams to use more effective and authentic assessment measures to identify and plan educational services for young children who have special needs. With an emphasis on using the Transdisciplinary Play-Based Assessment-2 process, the goal is for these teams to then serve as model programs and train other Local Education Agency (LEA) assessment teams in surrounding counties.

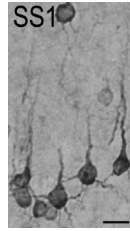
In addition, LINK provides team training on the best practices in the assessment of students with autism spectrum disorders. To date the program has trained over 80 teams from LEAs throughout North Carolina. The LINK team also contracts with families,

schools, and other agencies to consult on and assist with diagnostic assessments and treatment planning for students with significant and complex disabilities.

To learn more about the LINK program contact Becky Pretzel at Becky.Edmondson@CDL.UNC.EDU or Debbie Reinhartsen at Debbie.Reinhartsen@CDL.UNC.EDU.

Announcements:

- **Article published in the prestigious journal, *Neuron*:**
In this article, NDRC postdoctoral fellow Adam Roberts demonstrates that NR3A is an inhibitory regulator of synapse maturation and plasticity during early periods of brain development ([link to article](#)). This insight may help us understand synapse and memory dysfunctions associated with schizophrenia and a variety of neurodevelopmental disorders. This work was featured as a "Must Read" in [Faculty of 1000](#).
- **Exciting New Funding at the CIDD: A Family-Genetic Study of Language in Autism:**
The principal aim of this study, funded by the NIDCD, is to identify genetically meaningful language phenotypes among individuals with autism and their family members, for use in genetic studies and for target in future intervention work. Principal Investigator: Molly Losh (Dept. of Allied Health Sciences, UNC Chapel Hill) Co-Investigators at UNC: Peter Gordon (Psychology), Joe Piven (Psychiatry & CIDD), Patrick Sullivan (Genetics) Co-Investigator at the University of Iowa: Thomas Wassink (Psychiatry).
- **CDL Psychologist receives accolades:**
This past August, Greg Olley of the Center for Development and Learning became President of the Division on Intellectual and Developmental Disabilities of the American Psychological Association. Also in August, Dr. Olley was elected Vice-Chair of the North Carolina Commission on Mental Health, Developmental Disabilities, and Substance Abuse Services.
- **NDRC Investigator, William Snider, heads study that pinpoints a gene that controls the number of brain cells:**
The finding suggests that a single gene, called GSK-3, controls the signals that determine how many neurons actually end up composing the brain. This has important implications for patients with neuropsychiatric illness, as links have recently been drawn between GSK-3 and schizophrenia, depression and bipolar disorder. [Click here](#) to view video and write up on the UNC School of Medicine website.
- **Save the Date:**
Angelman Syndrome Conference will be held at the Carolina Inn, June 15-16, 2010.



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 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!

Philanthropic support is essential to the growth of the Carolina Institute for Developmental Disabilities and its goal of improving the quality of life for people with developmental disabilities across North Carolina and throughout the country.

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:" [Click Here](#).

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

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

Send us your comments:

We would love to hear from you if you have comments about our newsletter, ideas for potential articles, or if you would like to be added to our newsletter list! Drop us a line: info@cidd.unc.edu.

Many thanks to our newsletter article writers:
Keath Low and Julia Tarr