



Summer 2009

Inside the Institute

Improving Treatment for Children with Disabilities in Mexico



CDCSMA Students

Over the past year, several members of the UNC community led by Carolina Institute Director, Joe Piven, MD, have been working in partnership with the Centro de Crecimiento (Center of Development) in San Miguel de Allende (CDCSMA) Guajuato, Mexico to improve resources, education, and treatment services to families in the area. The CDCSMA acts as both a school and outpatient clinic providing much needed services to children with a wide range of disabilities, including autism, cerebral palsy, and Down Syndrome.

Debbie Reinhartsen, PhD, an Assistant Director and Speech-Language Pathology Section Head at the Center for Development and Learning (CDL) and Allison Bassett, psychology doctoral student and CDL trainee, recently returned from a week long volunteer trip to San Miguel. There they provided training in autism assessment methods and interventions to the CDCSMA

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An Exciting Discovery Leads to Hopeful Treatment Options for Angelman Syndrome

Angelman syndrome is a severe developmental disability characterized by outwardly normal development during the first year of life with a profound absence of subsequent cognitive milestones, including speech. This syndrome is caused by a maternally-inherited mutation or deletion in UBE3A, a gene also implicated in autism.

A major goal of research in Angelman syndrome is to understand how the absence of UBE3A alters development of the neocortex, an area of the brain important for cognitive abilities. Researchers within the Carolina Institute believe they may have found an answer.



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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

30th Annual TEACCH Conference: Reflections on 30 years of Autism Research and Practice

In May, TEACCH (Treatment and Education of Autistic and related Communication-handicapped Children) held its 30th annual conference at the Friday Continuing Education Center in Chapel Hill. The conference featured presenters who began their study of autism with TEACCH, and are now leaders in the field helping to enhance awareness, treatment and research of autism spectrum disorders. Centering on the theme of integrating research, practice methods and treatment techniques in order to best serve families and individuals affected by autism spectrum disorders, the list of dynamic speakers included:



Loisa Bennetto, Ph.D., Associate Professor of Psychology and of Brain & Cognitive Sciences, and Director of Clinical Psychology Training at the University of Rochester, who spoke on nonverbal communication in autism.

Geraldine Dawson, Ph.D., Research Professor in the UNC Department of Psychiatry and Chief Science Officer of Autism Speaks, who addressed new findings and future directions in autism research.

Laura Klinger, Ph.D., Associate Professor in the Department of Psychology at the University of Alabama and Director of the UA Autism Spectrum Disorders Research Clinic, who focused on learning disabilities in intuitive learning and implications for treating social skills impairments in ASD.

Sally Ozonoff, Ph.D., Endowed Professor and Vice Chair for Research at UC Davis' MIND Institute and practicing

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Center for Development and Learning Training Program

The Carolina Institute's Center for Development and Learning (CDL) provides interdisciplinary leadership development training opportunities for individuals at the master's, pre-doctoral, doctoral, post-doctoral, and professional levels. The training is offered in 12 disciplines of study that are designed to foster leadership skills in the areas of training, education, research, community-outreach, technical assistance, public policy, advocacy, systems administration, and clinical practice. Over 200 individuals receive leadership development training in this program each year.



Julie Hammer, Ph.D.

One component of the program matches trainees with area community partners or CDL faculty to collaborate on an initiative/research project to enhance the trainee's knowledge of public policy, advocacy and systems administration. CDL trainee, Julie Hammer, Ph.D., a post-doctoral fellow in psychology at the CDL, just completed her project with the Mead-Johnson study examining intelligence, attention, and memory in typically developing toddlers, age 18-24 months. Jackie Zins, a student working towards her

master's of education in school psychology, helped to develop a

qualitative assessment tool to be used during educational evaluations.

Zins also participated in the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Program this year and the experience is one she values greatly. "My knowledge in the area of service, policy, family-centered care, and interdisciplinary practice as it pertains to persons with developmental disabilities has grown exponentially as a result of my LEND traineeship," says Zins. "At the CDL alone, the LEND trainees strengthen their commitment to work with and for persons with disabilities, enhance their knowledge of developmental disabilities, and gain experiences they would never find elsewhere."

With their experiences at the CDL, Zins, Hammer, and other CDL trainees will continue into their professional careers as the next generation of leaders to better serve infants, children, and adolescents who have, or are at risk for developing neurodevelopmental and related disabilities and their families.



Jackie Zins



From the Desk of the Director

It is a great pleasure to tell you about the many and varied clinical and research training programs at the Carolina Institute. The breadth of these programs underscores the truly interdisciplinary nature of our efforts. Our trainees are the life-blood of our work – continuously challenging us to be better by questioning our clinical and research findings, disseminating new knowledge to our community and providing a steady stream of enthusiasm and energy to support all of our activities.

Closest to my personnel efforts is the NDRC NIH-funded T32 research training program in neurodevelopmental disorders, which I co-direct with Dr. Ben Philpot. Now in its 8th year of funding, this program provides two years of support for six post-doctoral research fellows to study with a research mentor, attend a didactic seminar series and obtain complementary clinical and laboratory experiences outside of their mentor's laboratories.

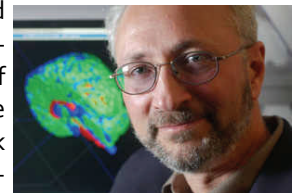
This years' group has covered a wide range of research relevant to neurodevelopmental disorders, from basic neurobiology to clinical studies. Our current and future group of outstanding post docs are profiled in this issue of the newsletter on page 5.

The CDL boasts numerous training programs – too many to review in this brief letter. Training is one of the defining features of the CDL, particularly through the federally-funded LEND (Leadership Education in Neurodevelopmental Disorders) Program directed by Steve Hooper, Ph.D. and Angela Rosenberg, Ph.D. The LEND Program focuses on the development of clinical expertise and leadership skills in the context of an interdisciplinary services model. The CDL provides training

at UNC to over 200 trainees per year in a variety of disciplines. As part of the LEND program, the CDL is launching a new core graduate course this fall in developmental disabilities involving problem-oriented, evidence-based approaches to specific clinical issues in developmental disabilities, within a family context

Clinical training activities also are a mainstay of the TEACCH Program. TEACCH faculty member, Dr. Gladys Williams directs a very popular undergraduate psychology course on 'Autism', and oversees a psychology internship (through the Department of Psychology), which provides highly sought-after, one year clinical internships to psychology graduate students at both TEACCH and the CDL. Through funding as well as clinical research oversight by Dr. Gary Mesibov, TEACCH annually supports a psychology graduate student to study in an autism related area, as well as 1-2 post-doctoral fellows. Finally, UNC child and adolescent psychiatry residents obtain clinical training in the TEACCH Medical Evaluation Clinic, and Family Practice residents regularly rotate through TEACCH for additional clinical experience. TEACCH also offers extensive training and educational experiences to providers in the community, both locally and throughout the world.

It is my hope that with additional layers of organization through the Carolina Institute, these varied and rich training experiences will be integrated so that ultimately 'the whole of our training enterprise will truly be greater than the sum of the parts'. I look forward to working with all of you to accomplish this exciting prospect.



By Joe Piven, M.D.

Supporting North Carolina Families With Children Who Have Special Needs

Learning that your child has a disability, a chronic illness or any other special health care need can be an emotionally charged time of adjustment for a parent. There may be a period of sadness and mourning as the parent comes to terms with the diagnosis and the challenges that lie ahead. It is easy to become overloaded with information. Research has found that one of the most valuable resources during this transition time is parent to parent support - the opportunity to talk to another parent who has "coped and survived."

The Carolina Institute's Family Support Network (FSN) supports this unique service through Support Parent Training, using the curriculum which has been developed by the FSN and is available in both English and Spanish. In addition, the FSN conducts the Train the Trainer sessions that help local Family Support

Network affiliates to use the materials. FSN also facilitates access to a national listserv of parents who have gone through Support Parent Training. Access to this listserv ensures that North Carolina parents can be matched with a trained, experienced parent whose child has a similar disability.

Parent to Parent Support Training is just one of the many ways Family Support Network promotes and provides support for families with children who have special needs. One parent describes herself as feeling overwhelmed and alone, as though she was in a sea drowning, after her child was newly diagnosed. Through involvement in Parent to Parent and other programs supported by FSN, however, she explains that she was not just given a life preserver, but was pulled into a life boat where she no longer felt isolated and alone.

Improving Treatment for Children with Disabilities in Mexico continued

staff and also led a conference on autism symptoms and treatment strategies for parents and professionals from the surrounding area. In addition, Dr. Reinhartsen and Ms. Bassett provided training in general early intervention strategies for a wide range of developmental disabilities and they continue to support the CDCSMA through teleconferences.

Hola Debbie y Allison,

You can't imagine what this visit has done for all of us. As you noticed, our team is a very young one (except for me, ha, ha) and you encouraged them to continue learning and fighting for what they expect from themselves. You motivated them to make changes for a new future in each of their children - and to start right now. Even people who attended your conference have called to congratulate you again through ourselves. We are very grateful to both of you, as well as Dr. Piven for letting you come. Thank you for all you've shared with our team. We're looking forward to seeing you very soon again.

*We send you both our love,
Dulce*

Dulce Maria Fernandez, author of the letter above is a retired special education teacher who volunteers at the CDCSMA. Fernandez's letter is just one of several similar letters of thanks and appreciation sent by the community in San Miguel. Research, service, education, and personal connections just like these – this is what makes the Carolina Institute and its people so unique and their work so valuable.



The Centro de Crecimiento is staffed exclusively by volunteers and is funded solely through donations. Monetary support to the CDCSMA ensures that the children at the center get the proper care, that staff have the materials they need, and helps fund more training visits. If you are interested in contributing, please contact Debbie.Reinhartsen@cdl.unc.edu

Treatment Options for Angelman Syndrome continued



Ben Philpot, Ph.D.

Collaborative research from the labs of Ben Philpot, PhD, an Assistant Professor of Cell and Molecular Physiology and co-director of the Neurodevelopmental Disorders Research Center post-doctoral research training program, and Mike Ehlers, MD, PhD, a Professor at Duke University, has found that brain cells in Angelman syndrome model mice lack the ability to appropriately strengthen or weaken in the neocortex.

Normally, babies learn and process information about the world around them through touch, sight, and sounds. Through this sensory experience neuronal connections and disconnections are made within the brain, and these changes in neuronal connections form the building blocks for learning. "By strengthening and weakening appropriate connections between brain cells, a process termed synaptic plasticity, we are able to constantly learn and adapt to an ever-changing environment," explains Philpot, senior author of the study published in the June issue of Nature Neuroscience. [Full Text - Ube3a is required for experience-dependent maturation of the neocortex.](#)

If brain cells do not have the ability to encode information and modify their connections based on an individual's sensory experiences, problems in learning result. Philpot and Ehlers' research finds that synaptic plasticity is severely impaired in Angelman syndrome model mice deficient in the UBE3A gene.

Excitingly, the research groups of Philpot and Ehlers have discovered that normal brain plasticity can be restored by sensory deprivation. This raises the remarkable possibility that brain cells in Angelman syndrome patients maintain a latent ability to reverse their plasticity defects, and this potential to restore plasticity may be achieved through behavioral, pharmacological, or genetic manipulations to offer a unique opportunity to treat Angelman syndrome.

This same experimental approach should also reveal how brain cells encode information from experiences in other related disorders, such as autism, and may provide a model to find interventions for a variety of neurodevelopmental disorders.

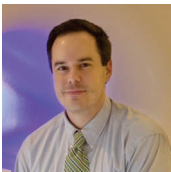
NIH T32 Postdoctoral Research Training

The research arm of the Carolina Institute provides state-of-the-art training for post doctorates working in the field of developmental disabilities. The mission of the Postdoctoral Research Training Course is to develop researchers with expertise in both the biological basis and clinical manifestations of neurodevelopmental disorders. This broad-based and integrated perspective enables researchers to better relate across disciplines and maximizes the potential for major research advances in understanding the pathogenesis and treatment of these disorders. The Carolina Institute is thrilled to welcome three new post docs and is honored to continue training three post docs in their second year of the program.

Incoming Post Doctorates:



Sarah Short earned her Ph.D. from the University of Wisconsin, Madison, in Biological Psychology with a specialty minor in Neuroscience. Dr. Short will partner with John Gilmore, M.D. and colleagues during her postdoctoral training at UNC. Dr. Short's research efforts will be aimed at characterizing brain development from the prenatal period through early childhood.



John Anthony Richey, Ph.D., will join the NDRC postdoctoral training program with a doctorate in clinical psychology from Florida State University. Dr. Richey will be examining the neural substrates of social cognition in Williams Syndrome using fMRI, and examining the biological mechanisms of change in neurocognitive intervention for autism and social phobia. Gabriel Dichter, Ph.D. and Jim Bodfish, Ph.D., will serve as co-mentors to Dr. Richey during his post-doctoral training in neurodevelopmental disorders translational research.



Portia McCoy, Ph.D., received her doctorate degree from the University of Alabama, Birmingham. She will continue her postdoctoral research in the Department of Cell & Molecular Biology together with Ben Philpot, Ph.D., Associate Director of the NIH T32 Post Doctoral Research Training program. Her research interests include defining the synaptic deficits underlying a genetic form of autism in the hopes of developing new therapies while expanding our understanding of the disorder at a molecular level.

Continuing Post Doctorates:



John Allen received his Ph.D. in Physiology and Biophysics at the University of Illinois-Chicago College of Medicine in 2007. He begins his second year as a post-doctoral research fellow in the NDRC training program under the direction of Bryan Roth, Ph.D., M.D., in the Department of Pharmacology, studying the neuropharmacology and signal transduction of serotonin receptors. Dr. Allen is testing both existing and new antipsychotic and antidepressant drugs in pre-clinical mouse models of both schizophrenia and the neurodevelopmental disease Coffin-Lowry syndrome. The overall goal of this work is to discover biochemical pathways, essential genetic factors, and behavioral correlates in mice that will predict drug effectiveness for the treatment of both psychosis and cognitive impairments. His research is also actively involved in drug discovery and drug screening for new antipsychotic and antidepressant medicines.



Deb Childress received her doctoral degree in Developmental Psychology at UNC-Chapel Hill. She is entering her second year in the NDRC post-doctoral training program under the mentorship of Joe Piven, M.D., Director of the Carolina Institute and Professor of Psychiatry, Pediatrics and Psychology. Dr. Childress is working on two studies utilizing imaging (sMRI/DTI and fMRI) and behavioral measures. The focus of her work is integrating information from the imaging and behavioral protocols in two studies; one focusing on infant siblings of children with autism and the other examining the broad autism phenotype in parents of children with autism.



Adam Roberts, Ph.D., is pursuing research seeking to understand how sensory experiences leave their trace on the brain. He is entering his second year in the NDRC post-doctoral training program in the Department of Cell and Molecular Physiology under the mentorship of Ben Philpot, Ph.D. Experience-dependent modifications in the brain are essential for establishing proper neural circuits during development as well as for encoding memories throughout life. Deficits in experience-dependent synapse development underlie many neurodevelopmental disorders. By investigating these disorders Dr. Roberts hopes to learn more about fundamental nervous system function, as well as work towards the amelioration/prevention of these disorders.

Announcements:

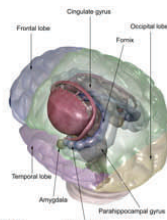
- **Carolina Institute for Developmental Disabilities new website:** www.cidd.unc.edu
Be one of the first to explore the new CIDD website and learn about everything from our current clinical services, to a full staff and faculty directory, to our latest research projects.



- **Pediatric Acquired Brain Injury Plan:**
The Center for Development and Learning (CDL), has been selected by the Sarah Jane Brain Foundation (SJBF) to be the State Lead Center of Excellence for North Carolina. The SJBF has funded State Centers of Excellence in every state as well as Washington DC and Puerto Rico in an effort to develop a national coordinated effort to address the issues faced by children and adolescents who have sustained a brain injury and their families. [Read More](#)



- Neuropsychological Profile of Autism and the Broad Autism Phenotype Study published in the [Archives of General Psychiatry](#) reveals further information about how a specific area of the brain that helps read facial cues is larger in toddlers with autism than in children without the disorder. Dr. Piven was interviewed in conjunction with this article for a spot on [CNN](#) and an article in the Raleigh [News & Observer](#).



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30th Annual TEACCH Conference continued

clinical psychologist, who addressed how autism emerges and the patterns of onset in the first years of life.

Wendy Stone, Ph.D., Professor of Pediatrics at Vanderbilt University and Director of the Treatment and Research Institute for Autism Spectrum Disorders, who discussed past, present and future early identification research.

The conference was well attended with a wide range of participants including researchers, physicians, psychologists, allied health professionals, teachers, parents, and others interested in the field of autism spectrum disorders. "It was a true honor to present at this year's conference, alongside other former TEACCH interns," says Dr. Stone. "This conference was a testimony to the contributions that TEACCH has made to the autism community." Alice Wertheimer, Training Coordinator UNC-Chapel Hill TEACCH Division, organized the conference.

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, Lauren Bomba, and Julia Tarr.

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.