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April is Autism Awareness Month!

ACT EARLY to Identify Autism Spectrum Disorders (ASD)

Autism Awareness Month offers a special opportunity to highlight the importance of early screening and diagnosis of ASD. The Centers for Disease Control and Prevention (CDC) estimates that 1 in 68 children in the United States has been identified with ASD, making it clear that autism affects the lives of millions of Americans – our neighbors, coworkers, friends and family members.

ASD is a developmental disability characterized, in varying degrees, by persistent difficulties in social communication and restrictive and repetitive behaviors, interests, or activities. Research has shown that early identification and intervention at younger ages can be quite effective and help promote optimal outcomes; to this end, knowledgeable professionals can often diagnose ASD as early as age 2.

One of the easiest and most effective ways of catching potential developmental delays, including ASD, is by monitoring developmental milestones. This can be done by parents, careproviders and other professionals and is the focus of the CDC's Learn the Signs. Act Early. campaign (LTSAE; <u>http://www.cdc.gov/ncbddd/actearly/</u>). LTSAE provides information and free materials to help parents track their child's development and reach out to professionals when there is a concern. Parents are also encouraged to ask for routine developmental screenings at well-child checks and to make sure their children are screened for ASD at their 18- and 24-month checkups.

As the NC Act Early Ambassador, Dr. Becky Pretzel can assist families and professionals in accessing (free) materials and spreading important messages about early awareness and developmental monitoring/screening. Additionally, the NC ASD State Implementation grant has printed LTSAE milestones brochures and booklets which can be shared on request. If you are interested in accessing some of these materials or have questions, please contact Dr. Pretzel at <u>becky.edmondson@cidd.unc.edu</u>.



A University Center for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD) with core funding from the Administration on Developmental Disabilities (ADD)

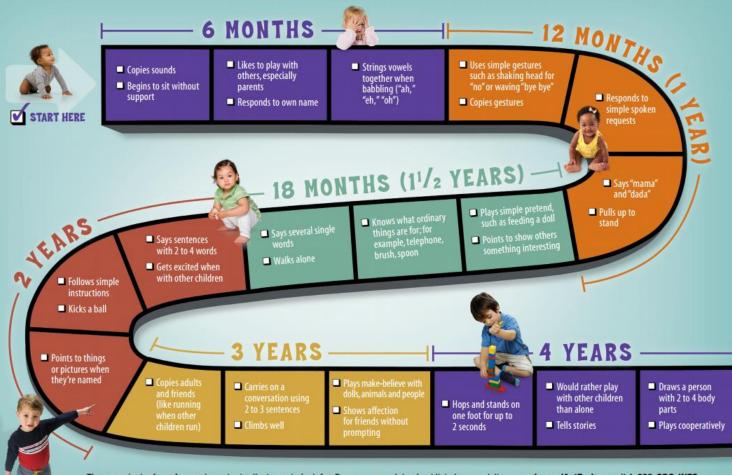




An Intellectual and Developmental Disabilitie Research Center (IDDRC) with core funding from the National Institute of Child Health and Human Development (NICHD) A Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Program with core funding from the Maternal and Child Health Bureau (MCHB)

Your Child's Early Development is a Journey

Check off the milestones your child has reached and share your child's progress with the doctor at every visit.



These are just a few of many important milestones to look for. For more complete checklists by age visit www.cdc.gov/ActEarly or call 1-800-CDC-INFO.

Autism Spectrum Disorder in Children With Hearing Loss

Carolina Institute for Developmental Disabilities (CIDD) faculty member, Margaret DeRamus, MS, CCC-SLP, is featured in the current issue of the American Speech-Language-Hearing Association (ASHA) publication, *The ASHA Leader*. Her article, "When It's More Than Hearing Loss," provides information about ways to be attuned to signs of autism spectrum disorder (ASD) in children with hearing loss.

"Often, we see families and professionals so focused on a child's hearing loss or other medical issues that they miss signs of ASD, leading to delayed initiation of ASD-specific interventions," writes Ms. DeRamus. "That's why we recommend that audiologists and speech-language pathologists who work with children with hearing loss be on the look-out for signs of ASD and, when noticed, refer the child for a skilled assessment as early as possible."

Children with hearing loss are at a higher risk for ASD and a number of other developmental disabilities. <u>The Hearing and Development Clinic</u> at the CIDD was established to address such co-existing conditions. To learn more about the signs of ASD in children with hearing loss, read the complete *ASHA Leader* article, "<u>When It's More Than Hearing Loss</u>."



Margaret DeRamus administering the Autism Diagnostic Observation Schedule

(DeRamus, M. (2015). When it's more than hearing loss. The ASHA Leader, 20(4), 10-11. doi:10.1044/leader.FMP.20042015.10)

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CIDD and University/Community Partners Offer ASD Education

Two federal grants have generated opportunities for CIDD faculty and colleagues to provide collaborative statewide education and outreach on the early identification and diagnosis of ASD.

A primary source of support for ASD training is the NC ASD State Implementation Grant (SIG; PIs: Stephen Hooper and Becky Pretzel) which is focused on decreasing the average age of ASD screening and diagnosis. As such, several activities have been implemented with other state agencies and colleagues.

Children's Developmental Services Agencies (CDSA) - The CIDD, in partnership with the ASD State Implementation Grant, sponsored two 2-day training workshops on the clinical use of the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2) for interdisciplinary early intervention teams in North Carolina (CDSA staff) and clinical fellows from the North Carolina Leadership Education in Neurodevelopmental and Related Disabilities (NC-LEND) program. The workshops were hosted by the Carolina Institute for Developmental Disabilities (CIDD) and taught by Pamela DiLavore, Ph.D., co-author of the original ADOS, Assistant Director of the Chapel Hill TEACCH® Center, and collaborator on the NC SIG. Over 50 professionals and graduate student clinicians attended, including psychologists, nurses, speech-language pathologists, occupational therapists and early special educators representing 12 CDSAs across North Carolina. To further assist with implementation into practice, the NC SIG faculty and Dr. DiLavore will continue to provide technical assistance through email and phone conferencing over the next year.



LEND trainees Angie Waitt and Ashley Costner learn about the ADOS2



Left to right: Becky Pretzel (CIDD), Kerri Erb (ASNC) and Lauren Turner-Brown (TEACCH)

<u>Managed Care Organizations (MCO)</u> – In partnership with the NC Council of Community Programs, Becky Pretzel (CIDD), Lauren Turner-Brown (TEACCH) and Kerri Erb (ASNC) provided a series of webinars and face-to face meetings with statewide MCO staff. Training focused on an overview of ASD, risks and red flags, cooccurring IDD and mental health conditions, and resources across the state.

<u>NC Pediatric Society</u> – In collaboration with the NC Pediatric Society, Becky Pretzel (CIDD), Betsy Crais (UNC Division of Speech and Hearing Sciences) and Dr. Marian Earls (Community Care of NC) provided an evening and breakfast session at the Winter Forum. The sessions focused on identifying ASD in young children and on evidence-based ASD screening using the MCHAT-RF. Additional sessions will be held at the Spring Forum in Raleigh on April 11, 2015 and at their annual conference this summer.

A second grant from the Association of Maternal and Child Health Programs (AMCHP) was awarded to Becky Pretzel (CIDD), Betsy Crais (UNC Division of Speech and Hearing Sciences) and Maureen Morrell (ASNC) to provide ASD training to faith-based groups in Cumberland and Robeson counties in efforts to reach minority and underserved families. Working collaboratively with local providers in Cumberland County, two workshops were held in Fayetteville, NC at Manna Church that provided an overview of ASD, with particular focus on early awareness and identification of ASD, as well as tips for fully including individuals with ASD and their families in the church community. The two workshops were attended by over 200 church and community members; interpreters were available to provide Spanish translation. Following these workshops, several organizations have indicated that they plan to develop a special needs ministry within their own faith community. This workshop will be repeated in Robeson County this fall.

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Autism Awareness Month 2015 Celebrates DIVERSABILITIES Featuring Artwork by Susan Kermon

Susan Kermon, a second year Leadership Education in Neurodevelopmental Disabilities (LEND) Self-Advocacy Trainee, is a featured artist and speaker at the FRANK Gallery on April 15 and at the Carrboro Branch Library on April 2 through June 14. The exhibitions are presented as part of *Diversabilities*, celebrating Autism Awareness Month 2015.

Ms. Kermon has a BFA in Sculpture from UNC-Greensboro and was diagnosed with autism spectrum disorder in February 2012. As a LEND Trainee mentored by CIDD faculty, Deborah Zuver, Ms. Kermon serves as an education coach and is a member of the NC Postsecondary Education Alliance team. During the April events, Ms. Kermon will discuss her process with art and the role that her LEND experience played in taking steps to exhibit her art for her first time.

"While awareness of autism has become mainstream, understanding has not," reflects Ms. Kermon. "My goal, as I learn more about myself and others, is that I will be able to refine my own way of communicating my reality successfully and perhaps help others to better see theirs. I have an artistic ability that was dominant by age 7 and that will always be a part of my life. I hope to incorporate visual language as yet another means of spreading insight and understanding to every facet of the community."



Photo by Barbara Tyroler



Photos by Barbara Tyroler

Barbara Tyroler's *Rockin' the Spectrum* on Display at the CIDD

In recognition of the CIDD's work with children with developmental and other disabilities, Barbara Tyroler is exhibiting her photos of the adapted aquatics program offered through Chapel Hill Parks and Recreation Adapted and Inclusion Programs. The photos celebrate children with autism and other developmental disabilities as they confront and overcome their fears of the water in an award-winning arts commission, *Rockin' the Spectrum*. Photos include quotes and comments. Families and the CIDD team have expressed delight and appreciation of these moving photos that are displayed in the CIDD reception area. Tyroler's background and approach are varied: artist, photographer, educator, and community worker. She coordinates outreach at FRANK Gallery in Chapel Hill and promotes advocacy in health and education by photographing children. Deborah Zuver, CIDD director of advocacy initiatives, assisted Tyroler in coordinating Autism Awareness Month events, which feature Susan Kermon, CIDD LEND trainee in self-advocacy.

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Survey to Gather Your Input

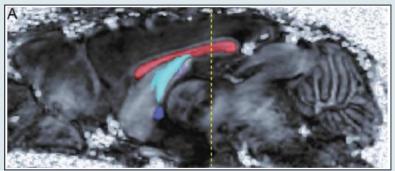
The NC Council on Developmental Disabilities (NCCDD) is developing its new five-year plan for 2016-2021. As specified by the Developmental Disabilities Act, the plan addresses the range of needs and issues for the DD community in North Carolina. A CIDD team (Deborah Zuver, Greg Olley, Morgan Parlier and Pete Duquette), in collaboration with the NCCDD, is finalizing a survey to collect input from individuals with IDD, their families, and professionals and community members who support them. Watch for an email next month with the survey link. Please respond to make sure your voice is heard.

CIDD Investigators Research Biomarkers for Angelman Syndrome

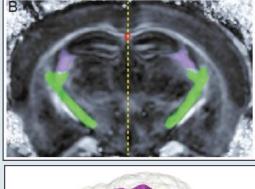
Microcephaly emerges during early postnatal life in most individuals with Angelman syndrome. To examine the basis and developmental emergence of this microcephaly, the laboratory of Dr. Ben Philpot is performing detailed brain analyses in Angelman syndrome model mice using a method of brain imaging, called Diffusion Tensor Imaging (DTI), light microscopy, and electron microscopy. In parallel, the laboratory of Dr. Heather Hazlett is performing non-invasive MRI and DTI imaging in children with Angelman syndrome to examine whether analogous deficits are observed in their brains. Mark Shen, a CIDD postdoctoral fellow mentored by Dr. Hazlett, will carry out the MRI and DTI analyses. These studies are expected to validate the utility of using DTI imaging as a biomarker for eventual clinical trials to treat Angelman syndrome.

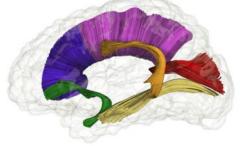
Dr. Hazlett will be enrolling 4-12 year old children with (genetically) defined Angelman syndrome to participate in the study. Enrollment begins May 1st, and participation involves a one-time visit to UNC for behavioral assessments and an MRI-DTI scan of the brain. Families will be reimbursed for travel and related expenses, and the assessment and MRI scan are provided at no cost to the family. For more information on enrollment, please contact Heidi Bryant McNeilly (study coordinator) at <u>heidi.bryant@cidd.unc.edu</u> or (919) 966-5278. Families are also being recruited with the help of the UNC Angelman Syndrome Clinic.

In addition to the clinical phenotypes we will examine at UNC, additional clinical phenotypes amenable to therapeutic intervention will be explored through our collaborator, <u>Dr. Ron Thibert</u>, at the Angelman Syndrome Clinic at the Massachusetts General Hospital.



The Philpot lab has identified deficits in brain connectivity in the Angelman syndrome model mice (above images). The Hazlett lab will use DTI in children with Angelman syndrome to determine whether these same connectivity deficits can be detected in children with Angelman (right image). The overarching goal of the study is to validate the utility of using DTI imaging as a biomarker for eventual clinical trials to treat Angelman syndrome.





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CIDD Welcomes Psychiatrist Laura Politte, MD



Laura Politte, MD is a child and adolescent psychiatrist who joined the faculty at the CIDD in November 2014. She has been evaluating and treating both children and adults in her medication management clinic as well as participating in the Behavioral Medicine Clinic. Dr. Politte has a background in clinical trials for children and adults with autism spectrum disorders, and she hopes to continue her work in clinical trials at UNC as well. She also spends one day each week completing psychiatric and neurodevelopmental consultations in the UNC Hospitals pediatrics sub-specialty clinic, where she is involved in teaching pediatric residents on their developmental and behavioral pediatrics rotation.

Prior to moving to NC, Dr. Politte worked for 3 years at the Lurie Center for Autism, a clinical and research center for individuals with developmental disabilities at Massachusetts General Hospital, providing clinical care and participating in clinical trials. She has presented at national and international conferences regarding the process of obtaining informed consent for individuals with ID/DD to participate in clinical trials, and she has published a number of review papers related to the treatment of autism spectrum disorders and related disorders, such as Fragile X Syndrome.

Dr. Politte is a member of the American Academy of Child and Adolescent Psychiatry and serves on the editorial board of the Journal of Autism and Developmental Disorders. Her clinical work in Massachusetts also included a position as a consultation-liaison psychiatrist at Newton Wellesley Hospital and serving as a psychiatric consultant to wrap-around community mental health teams in two regions outside of Boston. Dr. Politte completed her residency in adult psychiatry and fellowship in child and adolescent psychiatry at Massachusetts General Hospital and McLean Hospital in Boston, MA, graduating in 2011. She is board-certified in both adult and child/ adolescent psychiatry by the American Board of Psychiatry and Neurology. She graduated from the UNC School of Medicine in 2006 and from UNC in 2002 with a B.S. degree in psychology and minors in biology and chemistry. Dr. Politte grew up in Raleigh, NC and is glad to be home!

Debbie Reinhartsen, PhD, Completes Advanced Training

The CIDD is pleased to announce that Dr. Debbie Reinhartsen recently completed the advanced training necessary to become a certified PODD (Pragmatic Organization Dynamic Display) trainer. To achieve this level of expertise on the PODD, Dr. Reinhartsen attended intensive trainings in Seattle and Maryland, conducted an in-depth case study and co-presented with Dr. Gayle Porter, developer of the PODD. She now joins a handful of recognized trainers in the United States who have the qualifications and experience to teach others to use this comprehensive communication system. The PODD is a way of organizing whole word and symbol vocabulary in a communication book or speech generating device in order to provide immersion and modeling for learning. The aim of the PODD is to provide vocabulary for continuous communication at all times, using a range of messages across a range of topics in multiple environments. It enables more effective communication and assists an individual in their understanding of other people's spoken language.

Dr. Reinhartsen has a rich background in alternative and augmentative communication (AAC) and assistive technology (AT) and is the Assistive Technology Lead at the CIDD. She provides services to individuals with a variety of complex communication needs and intellectual/developmental disabilities who may benefit from aided language or



communication strategies/devices. Through numerous contracts within the state, she provides education and training to interdisciplinary service providers as well as training to individuals and families on the assessment for and implementation of AAC/AT. Her expertise in this area is widely recognized across the state and adding the PODD certification to her repertoire allows another avenue for her to serve children and families in NC, as well as those throughout the country.

Dr. Reinhartsen will be conducting a two-day Introductory PODD workshop on Oct 15-16. If you would like more information on this workshop or on the PODD, please contact Dr. Reinhartsen (<u>Debbie.reinhartsen@cidd.unc.edu</u>).

Translational and Clinical Sciences (TraCS) Pilot Award to Explore Repetitive Motor Behaviors





Rob Christian and Anne Wheeler

Dr. Robert B. Christian, MD (CIDD) and Dr. Anne Wheeler, PhD (of both CIDD and Research Triangle Institute) in partnership with Dr. Sonia Grego of Research Triangle Institute (RTI) have been awarded a \$50,000 Translational and Clinical Sciences (TraCS) Pilot award. The team will be exploring the use of sensor enabled measurement of repetitive motor behaviors in the IDD population. Repetitive motor behaviors, also called stereotypies, are common in the IDD population and are a core feature of ASD. Currently the primary means of evaluating these behaviors in research and in clinical practice is via direct observation or via the use of caregiver completed rating scales. The eventual goal of the effort is to determine if a computer and sensor enabled measurement device can perform as well or better than the traditional means of evaluating these motor behaviors. Such an outcome measurement device could one day prove important in the evaluation of interventions intended to alter the core features of a neurodevelopmental disorder.

In the initial phase of the effort, the team will be using existing commercially available wearable accelerometers to collect movement data. Accelerometers are small instruments that can detect movement in various planes of motion. The subjects will be videotaped and their movements will be annotated by the research team. The information collected will assist Dr. Grego's team at RTI in developing a teachable computer algorithm such that the device can be "taught" to recognize an individual's movements reliably and consistently. The device would then be tested in natural environments in phase II of this effort.

While CIDD and RTI have collaborated before, this stands as one the first efforts by CIDD to partner with bioengineers at RTI around a project focused on outcome measurement development specifically for the IDD population.

Our Social Smarts Spring Group Starts Soon!

This educational series for children ages 5 to 8 years and their parents is designed to help improve your child's social smarts, social curiosity, and social engagement. Our Social Smarts group, based on Michelle Garcia Winner's Social Thinking® model, will provide structured practice of social thinking skills in a positive, supportive, and kid-friendly environment. Using *The Incredible Flexible You* curriculum children learn to use their social thinking tools while on fun imaginary journeys to places like a farm and outer space. In addition, children learn about identifying their emotional states, or "zones" (based on the *The Zones of Regulation*), and strategies to move from one zone to another to self-regulate. The group also incorporates parent education and support through weekly parent sessions, which will run concurrently with the child group. This unique model will provide parents the opportunity to both observe and participate in their child's social learning.

Child Group Facilitators: Margaret DeRamus, MS, CCC-SLP; Angie Waitt, MS, CF-SLP Parent Group Facilitators: Sherry Mergner, MSW, LCSW; Morgan Parlier, MSW, LCSW

We're also excited to announce that our Social Smarts camp will be coming back this summer with both morning and afternoon sessions the week of July 27-31! The camp incorporates the same curricula as the group and is open to children ages 4 to 8. Please look for more information regarding the camp sessions in May.

For more information about the camp or other Social Smarts programs at CIDD, please contact Margaret DeRamus at margaret.deramus@cidd.unc.edu.



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MRIs Link Impaired Brain Activity to Difficulty Regulating Emotions in Autism

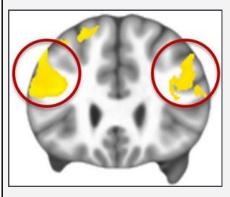
Tantrums, irritability, self-injury, depression, anxiety. These symptoms are *associated* with autism, but they're not considered core symptoms of the disorder. Researchers from the UNC School of Medicine are challenging this assertion. They have used functional MRI to show that – when it comes to the ability to regulate emotions – brain activity in individuals with autism is significantly different than brain activity in individuals without autism.

The findings, published in the *Journal of Autism Developmental Disorder* as part of a special issue on emotion regulation, suggest that improving prefrontal cortex activity could directly help individuals with autism regulate their emotions and improve serious symptoms associated with the disorder, which affects millions of people in the United States.

The discovery shows that "emotion regulation" symptoms have a biological explanation that can be visualized using fMRI. The symptoms do not seem to be merely associated with or a result of the core autism symptoms, which include repetitive behaviors, verbal and non-verbal communications problems, and difficulties with social interactions.



Gabriel Dichter, PhD



The yellow areas represent a composite of fMRI scans showing the areas of the prefrontal cortexes that are significantly less active in people with autism during emotion regulation.

CIDD investigator and Associate Professor of Psychiatry

Gabriel Dichter, PhD, is senior author of the paper. The first author is Dr. John Richey, former postdoctoral fellow in Dichter's lab who was part of the CIDD's T-32 training program. He is now an assistant professor at Virginia Tech. Current CIDD intern, Cara Damiano, and former CIDD graduate student, Anna Sabatino, are also authors.

"This research adds to the growing awareness that although autism is diagnosed on the basis of social impairments and repetitive behaviors, the importance of emotion regulation and all the behaviors that come with it – depression, tantrums, meltdowns, irritability – are very real and should be a focus of clinical services," said Dr. Dichter. "Any parent of a child with autism knows that these symptoms can be pervasive. Children with autism often lack the ability to cope with difficult emotional situations, often resulting in meltdowns and tantrums that are very challenging for the family."

There are only two FDA-approved medications to treat autism, and neither treats core symptoms; they treat high levels of irritability and aggression. "We've known for a while that we need to pay attention to emotion regulation in people with autism," Dichter said, "but we think these data suggest a neural basis for these problems and add credence to the idea that they may be a core feature of the disorder."



Michelle Franklin, MSN, Leads Healthcare in Developmental Disabilities Curriculum Development Effort

Michelle Scotton Franklin, MSN, 2014 graduate of the North Carolina Leadership Education in Neurodevelopmental Disabilities (LEND) program, is leading a curriculum development effort regarding healthcare in developmental disabilities. This is a curriculum directed towards the training of nurse practitioners. Associate LEND Director, Rob Christian, MD, is advisor on the project.

Ms. Franklin was recruited for this effort by the American Academy for Developmental Medicine and Dentistry. The healthcare in developmental disabilities curriculum development is a joint effort between AADMD, CIDD, and the Developmental Disabilities Council of Florida. Ms. Franklin is now our LEND community Nurse Practitioner faculty member.

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CIDD Interdisciplinary LEND Cohort Includes Self-Advocate Trainees



Catherine (Katie) Houser, a self-advocate trainee for 2014-15, sought the LEND fellowship in order to learn about current issues and challenges related to disability support. Katie is a graduate of Louisburg College and UNCG, with a B.S. in Human Development and Family Studies. The LEND (Leadership Education in Neurodevelopmental Disabilities) program at the CIDD is nationally recognized for its interdisciplinary leadership training. In 2010, the CIDD developed the first graduate-level training opportunity in the country for selfadvocates, a model now replicated at other universities. Deb Zuver and Donna Yerby are Katie's LEND mentors.

During her experience with Partners in Policy Making through the NC Council on Developmental Disabilities, Katie made a decision to relate her own life experiences to advocate for others. "It gave me a head start on LEND in understanding policy issues and being able to influence others." The LEND requirements include a problem-based graduate level course, Developmental Disabilities Across the Lifespan. Katie stated that the class was "intense" but she was surprised at how receptive the other students were to her ideas. Katie has appreciated having a "great" education coach, Susan Kermon; support has faded in the second semester as Katie has become more independent in meeting course requirements.

Additional LEND activities included presentations with the STIR (Steps Toward Independence and Responsibility) team, and Katie interviewed a previous LEND Self-Advocate for a research project. Katie noted that the Leadership Consortium, an additional component of LEND training, has given her tools, not just for leadership, but for life.

Katie credits her parents for early intervention as they were told by a doctor that she would not walk or talk, and they did everything in their power to make sure that didn't happen. "Boy, was he wrong about that!" Katie started advocating for herself at an early age. At the age of five, she was determined to play softball and has been advocating for her goals ever since. Katie's goals after leaving the CIDD are to get a good job and to become financially independent. She would like to own her own home one day. Above all, she wants to help others who have disabilities, and "just be happy."

CIDD Community Talk Series

The CIDD hosts a series of talks to share information about recent advances in developmental disabilities. These sessions are a great opportunity for parents, teachers, professionals, and others to learn more about specific developmental disabilities topics. All talks are free, and everyone is welcome.

Wednesday, April 8th

Robert B. Christian, MD Assistant Professor of Pediatrics and Psychiatry, CIDD, UNC School of Medicine

Rational Use of Psychopharmacologic Medication in The Context of Developmental Disabilities Dr. Christian will review general approaches to medication use in this population.

Sherry Mergner, MSW, LCSW

Wednesday, May 13th

Clinical Assistant Professor and the AHEC Liaison at UNC-CH, CIDD, School of Social Work

Let's Talk About It!

The Power of Promoting Disability Awareness

Ms. Mergner will focus on how to talk with a child about his/her disability as well as educating school administrators, teachers, staff and fellow classmates. A number of approaches will be examined highlighting the importance of the child becoming a self-advocate and a valued member of the school community.

Sessions are held from 7PM to 8:30PM at the CIDD. To RSVP or for more information, please contact Debbie B. Reinhartsen at (919) 966-4138 or <u>Debbie.Reinhartsen@cidd.unc.edu</u>

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Leah Townsend Receives National Research Service Award

Fourth-year Neurobiology Curriculum student, Leah Townsend, has received a National Research Service Award from the National Institute of Child Health and Human Development. Leah is mentored by Dr. Spencer Smith. Her study is titled, "Stimulus-driven cortical circuit deficits in a mouse model of Angelman Syndrome."

Angelman Syndrome (AS) is a severe neurodevelopmental disorder caused by disruption of a known gene called UBE₃A. In this project, Leah will use state-of-the-art in vivo twophoton calcium imaging to determine the deficits of neuronal circuitry in a mouse model of AS. This work is at the frontier of understanding neurodevelopmental disorders because it will measure neural circuit function in living mice, with single neuron resolution during sensory processing, and determine what aspects of neural circuit function fail to properly develop in AS.



Rachel Greene Receives TraCS Funding to Evaluate Eyetracking as an Outcome Measure for Autism Treatments



First-year clinical psychology doctoral student Rachel Greene has been awarded a North Carolina Translational and Clinical Sciences (TraCS) grant to collect pilot data to evaluate eyetracking as an outcome measure for autism treatments. Rachel's research mentor is CIDD investigator Gabriel Dichter, Associate professor of Psychiatry, and this research will dovetail with Dr. Dichter's social skills group at the CIDD.

A well-known barrier to developing novel autism intervention is the lack of established outcome measures for autism treatments. Most autism clinical trials rely on clinical observation or caregiver reports of symptom improvements. But clinical observation is often not a sensitive index of treatment response, and caregivers may not be able to detect subtle changes in symptoms that may occur during the course of a clinical trial. For these reasons, robust and objective markers of social-communication functioning that are sensitive to change would increase the pace of discovery of novel autism treatments.

Rachel plans to collect eyetracking data before, immediately after, and then 6-months after adolescents and young adults with autism participate in Dr. Dichter's social skills group intervention at CIDD. This intervention was developed in collaboration with CIDD investigators Drs. David Penn and Lauren Turner-Brown and has been offered by the

CIDD as a clinical service since 2011. Rachel plans to relate changes in visual social attention detected by eyetracking with changes in caregiver report, self-report, and neuropsychology measures of emotion recognition and emotional understanding in higher-functioning and verbal adolescents and young adults with autism before evaluating the measure in younger and/or non-verbal children with autism.

Rachel will be using an eyetracking paradigm developed by Dr. Robert Schultz at the Children's Hospital of Philadelphia that depicts children interacting in dynamic play, and the project is also a collaboration with Dr. Edwin Brodkin at the University of Pennsylvania, who recently was award a Pilot Effectiveness Studies and Services Research Grant (R₃₄) to implement CIDD's social skills group as part of a program of vocational rehabilitation for adults with autism at U Penn.

The data collected by this TraCS award will be pilot data for larger foundation and federal grant applications to further refine the capacity of the eyetracking measure to be sensitive to change in autism symptoms due to targeted autism treatment.

First Two CIDD Trainees Complete CIDD's Certificate Program in Developmental Disabilities

In the Fall of 2013, the CIDD established a Certificate Program in Developmental Disabilities. This certificate is directed by CIDD Investigator, Dr. Gabriel Dichter, and supports the learning objectives of the North Carolina University Center for Excellence in Developmental Disabilities (NC-UCEDD) at the CIDD.

Components of this 2-year program include: (1) coursework in disease etiology and mechanisms; (2) interdisciplinary exposure to developmental disabilities training; (3) improved understanding of the presentation of different neurodevelopmental disorders; (4) exposure to systems and family issues; (5) training in cultural diversity; (6) didactics in neuropsychological assessment in neurodevelopmental disorders; (7) teachings in evidence-based treatment of neurodevelopmental disorders; and (8) ethics training.

This Spring, the program will graduate its first two students. Leslie Payne is graduating in the Masters of Social Work Program this year at UNC and was a CIDD LEND fellow in 2014 working with Sherry Mergner. Leslie is pursuing a clinical career in couples and family therapy specializing in families affected by developmental disabilities. Leslie will be joining the Duke Center for Autism and Brain Development upon graduation.

Adrienne Villagomez is a doctoral candidate in school psychology. Through a CIDD LEND fellowship in Special Education in 2012, she began her training at the CIDD and involvement in the North Carolina Postsecondary Education Alliance. Since her LEND fellowship, she has worked on a UNC-CIDD and RTI research study on Decisional Capacity and Informed Consent in Fragile X Syndrome. Her dissertation examines self-determination in adolescents and adults with FXS. Adrienne is completing her predoctoral internship at UNC next year and hopes to continue to work within the UCEDD network in the future.

For more information about the CIDD's Certificate Program in Developmental Disabilities, please see <u>https://www.cidd.unc.edu/Education/default.aspx?id=50</u> or contact <u>dichter@med.unc.edu</u>.



Leslie Payne



Adrienne Villagomez



NC-LEND Hosts Workshop on Cultural Competence

The NC-LEND program, in cooperation with UNC's Maternal and Child Health Leadership Consortium, hosted a daylong workshop on February 23rd led by Dr. Vivian Jackson (pictured left), a nationally renowned expert on cultural competence. Dr. Jackson is a member of the faculty of the National Center for Cultural Competence (NCCC) at Georgetown University's Center for Child and Human Development. *NCCC's mission is to increase the capacity of health care and mental health care programs to design, implement, and evaluate culturally and linguistically competent service delivery systems to address growing diversity, persistent disparities, and to promote health and mental health equity.*

Over 30 LEND trainees, fellows, and faculty were joined by graduate students from the Schools of Public Health and Social Work at the Sonja Haynes Stone Center for an informative and stimulating day that addressed topics ranging from implicit bias to analysis of cultural competence at organizational and systems levels.

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



Please Join the "UNC CIDD" Team at the Angelman Syndrome Foundation (ASF) Walk on Saturday, May 16, 2015 at the Imperial Center in Durham.

Use the following link to register and/or donate to our team goal: <u>http://secure.angelman.org/index.cfm?fuseaction=donordrive.team&teamID=7501</u>



CIDD Together with TEACCH "Light It Up Blue!" for 2015 World Autism Awareness Day

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