



ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES
RESEARCH, EDUCATION, SERVICE

LEND LINKS

News from MCHB

Denise Sofka and Madhavi Reddy, MCHB Project Officers

Happy New Year! It has been a busy winter for the MCH Training Program. We coordinated a LEND Genetics Planning Meeting on December 13, 2006 in Washington, DC. Ann Cox, PhD, RN facilitated the meeting and is preparing a final report that will be available in February on the AUCD website, <http://www.aucd.org>. On January 23-24, 2007, the MCH Leadership Competencies Workgroup will convene a meeting to review the current draft of the competencies. This product will be released at the Joint Meeting of MCH Training Interdisciplinary Programs on March 4, 2007 at the Crystal Gateway Marriott, Crystal City, VA. The Joint Meeting will focus on the goals of the MCH Training Strategic Plan.

In June 2006, we announced the formation of the **2006-07 Priority MCH Training Strategic Planning Workgroups** designed to provide training grantees with an opportunity to directly impact policies and procedures to guide the implementation of the Training Program and to assist with the achievement of the MCH Training National Strategic Plan goals and objectives. There are five workgroups – **Interdisciplinary Training & Practice, Family Centered and Family-Directed Care, Reporting and Monitoring, Trainee & Faculty Diversity, and MCH Leadership Competencies**. At the Joint Meeting, participants will break into five groups to review current products and provide feedback to existing workgroup members to facilitate future activities. Each group has been working to develop tools, definitions and guidelines that will be referred to in upcoming program guidance and used as a reference as the MCH Training Program develops future strategic plans and reporting requirements. You can view these workgroup products as they become available. The site can be accessed at <http://workgroups.mchtraining.net/>. An announcement will be made through the listserv to inform you when additional workgroup products are available and have been posted to the site.

We look forward to seeing you at the Joint Meeting!

Joint Meeting of MCHB Interdisciplinary Leadership Training Programs

MCHB STRATEGIC PLAN WORKGROUPS

March 4, 2007

Crystal Gateway Marriott Hotel, Crystal City, VA

To register and view logistic information for this, the **LEND Directors Meeting**, and the **OT & PT Discipline Meetings**, visit www.aucd.org.

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NETWORK NEWS

RTOI in Down Syndrome Health Education through AUCD-NCBDDD

Sue Lin, MS, Project Director, AUCD CDC Cooperative Agreement

AUCD is pleased to announce another NEW Research Topic of Interest (RTOI) opportunity in area of Down Syndrome Health Education through our cooperative agreement with the National Center on Birth Defects and Developmental Disabilities (NCBDDD) at the Center for Disease Control and Prevention (CDC). Letters of Interest (LOIs) for the 2007 AUCD-NCBDDD RTOIs are now being accepted!

- RTOI 2007-03: [Transforming Existing Down Syndrome Professional Education Training Tools for Broader Dissemination and Use](#)
- Funding Level: \$150,000-200,000
- Project Period: One year
- To view the full project description and more information on the application process, visit the AUCD website under "Projects"
- Deadline to submit a Letter of Interest for the Down Syndrome Health Education RTOI is **February 19, 2007**.

Year 2 PMUs Announced by AUCD and SSA

AUCD is pleased to announce the second round of Pediatric Medical Units (PMUs) that will work with the Social Security Administration (SSA) and state and federal adjudicators to ensure that the best decisions are made as early as possible in the process for children applying for federal disability benefits. The next round of prototypes will operate at the following four locations:

- JFK Partners, University of Colorado at Denver Health Sciences Center – Denver, CO
- Mailman Center for Child Development, University of Miami Miller School of Medicine - Miami, FL
- Institute on Disability and Human Development, University of Illinois at Chicago – Chicago, IL
- Nisonger Center, Ohio State University - Columbus, OH

These four PMUs will join the initial four that are already operating at these locations:

- Institute for Community Inclusion, Children's Hospital, University of Massachusetts - Boston, MA
- Center for Disabilities and Development, University of Iowa - Iowa City, IA
- Boling Center for Developmental Disabilities, University of Tennessee Health Science Center - Memphis, TN
- Center on Human Development and Disability, University of Washington - Seattle, WA

AUCD hopes to circulate a request for Statements of Interest for Year 3 in the fall of 2007. Pending budget authorization, we will add locations on an annual basis with up to 16 Centers/Programs participating by 2010.

CDC Launches Multi-state Study on Autism; \$5.9 Million Awarded to Five Sites

Centers for Disease Control and Prevention Press Release: Friday October 6, 2006

The Centers for Disease Control and Prevention (CDC) is initiating a multi-state collaborative study to help identify factors that may put children at risk for autism spectrum disorders (ASDs) and other developmental disabilities. Approximately 2,700 children, ages 2 to 5, and their parents will be part of this study.

CDC has awarded a total of \$5.9 million to five sites -- Kaiser Foundation Research Institute in California, Colorado Department of Public Health and Environment, Johns Hopkins University in Maryland, University of North Carolina at Chapel Hill, and the University of Pennsylvania. These sites make up the Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE) Network. CDC will also be participating in the study, and will include children and their parents from the metropolitan Atlanta area.

"We hope this national study will help us learn more about the characteristics of children with ASDs, factors associated with developmental delays, and how genes and the environment may affect child development," said Dr. Jose F. Cordero, assistant surgeon general and director of CDC's National Center on Birth Defects and Developmental Disabilities.

In this five-year study, The National CADDRE Study: Child Development and Autism, a number of factors will be studied for their potential association with ASDs, including:

- infections or abnormal responses to infections in the child, mother or father
- genetic factors in the child, mother and father
- mother's reproductive history
- abnormal hormone function in the child, mother or father
- gastrointestinal problems in the child
- family history of medical and developmental problems
- smoking, alcohol and drug use in pregnancy, and
- parent's occupation and other socio-demographic factors.

The CADDRE Network was established following the Children's Health Act of 2000 that directed CDC to establish regional centers of excellence for ASD and other developmental disabilities. For information on CDC's work on autism, please visit <http://www.cdc.gov/autism>.

NETWORK NEWS

Missouri Joins Forces with Kennedy Krieger to Accelerate Autism Research

Contact: Cheri Ghan, Director-External Relations, School of Health Professions, University of Missouri-Columbia

Bringing together families who deal with autism and researchers seeking answers about the neurological disorder is the goal as The Thompson Center for Autism and Neurodevelopmental Disorders joins with Baltimore's Kennedy Krieger Institute in the development of a state-level model for the Institute's national autism registry, the Interactive Autism Network (IAN). Thompson Center Director Janet Farmer announced the collaboration on October 10, 2006.

Kennedy Krieger's IAN project is a Web-based research initiative with both a research and community focus. The research arm of the project will provide a secure, online national registry where parents of children with autism and the nation's qualified researchers can connect and work together to learn more about the causes and treatments for the disorder. The online IAN community will provide a home for those that want to learn about the latest developments in autism research and care, share ideas and support others facing similar challenges.

Farmer says The Thompson Center, located at the University of Missouri-Columbia, had already been working with the Missouri Department of Mental Health to create a statewide voluntary autism registry. The Missouri Autism Project Registry will enable families to sign up and provide information such as when their family member was diagnosed, treatments and strategies tried and progress made. It also will allow them to submit their names for consideration for research projects. This project will be linked to the IAN national registry, building a model of how states can integrate IAN into their systems of care and expanding opportunities for autism research in Missouri.

The development of IAN was first announced earlier this year when the Kennedy Krieger Institute, one of the nation's leading treatment centers for autism and other neurodevelopmental disorders, received \$2.26 million from Autism Speaks to develop the open, interactive database. The funding was for the first year of a three-year commitment. Paul Law, director of medical informatics at Kennedy Krieger and assistant professor at Johns Hopkins University School of Medicine, Department of Pediatrics, is the principal investigator on the IAN project.

"What's most promising to me about IAN is its potential to accelerate the pace of autism research by making it more convenient for families to provide essential information that scientists can use to make new discoveries," says Paul Law. "Now, with the Thompson Center's help, we will create a model that can be replicated around the country, hopefully prompting even more parents of children with autism to become active and engaged in the cause."

The Missouri Autism Project Registry is under the direction of the Missouri Division of Mental Retardation and Developmental Disabilities (MRDD) in the Department of Mental Health. Farmer says the Thompson Center has built a partnership with the state to find ways to obtain accurate data on autism in Missouri that will guide policy making. "There's a clear partnership between the state of Missouri and the Thompson Center to not only find local solutions but to find statewide and national solutions to the challenges faced by families affected by autism spectrum disorders. This is one more tool we can use to do that," Farmer says.

According to Simons, the Missouri Autism Project Registry is a priority identified by a group of family members, state agencies and universities organized several years ago. "We are grateful for the dedication and vision of these people and are committed to identifying comprehensive and cost-effective methods to address the problems faced by families and people who live with autism. The partnership between MU's Thompson Center and Kennedy Krieger represents a truly unique opportunity for the State of Missouri."

About The Thompson Center

The Thompson Center for Autism and Neurodevelopmental Disorders, founded at MU in 2005, encourages developmental science research that contributes to the understanding of autism and other brain disorders. The Center brings together leading researchers and clinicians from six different MU schools and colleges. Their goal is to increase the availability of outstanding evidence-based care for persons dealing with autism and other neurodevelopmental disorders. For more information, visit <http://thompsoncenter.missouri.edu/>.

About Kennedy Krieger Institute

Internationally recognized for improving the lives of children with developmental disorders, Kennedy Krieger Institute in Baltimore, MD serves more than 12,000 children each year through inpatient and outpatient clinics, home and community services and school-based programs. Kennedy Krieger provides a wide range of services for children with developmental concerns mild to severe, and is home to a team of investigators who are contributing to the understanding of how autism develops, while pioneering earlier autism diagnosis and interventions. Through research studies, clinical evaluations and treatment, community programs and school settings, the Institute helps more than 2,000 children with autism each year. For more information, visit www.kennedykrieger.org.

NETWORK NEWS

Midwest LEND Consortium

Suzanne Pearson, IA-LEND Training Director

The Midwest LEND Consortium held its second annual meeting in Omaha, Nebraska on October 8-9, 2006. Faculty and trainees from Nebraska, South Dakota, Iowa, Kansas and Missouri gathered Sunday evening at the home of Dr. Cindy Ellis, Omaha Project Director, for refreshments and conversation. During informal introductions, faculty and trainees shared information about themselves and their professional interests in preparation for the all day seminar on Monday. Trainees and faculty were also honored to have Crystal Pariseau, LEND Coordinator for AUCD, in attendance for this meeting and were able to get better acquainted with her and learn about her role within AUCD.

On Monday, the group convened at the Durham Research Center, UNMC to learn about emergency preparedness issues for people with disabilities and to examine the emotional intelligence aspects of leadership. Madhavi Reddy, project officer from the Maternal Child Health Bureau, welcomed the group by teleconference and provided an overview titled, "MCHB: Overview, Objectives and Opportunities." Following this overview, trainees and faculty listened to a panel discussion on Interdisciplinary Perspectives on Crisis Leadership. The panel was represented by individuals from the following organizations: Medical Reserve Corp, Omaha Police Department, Omaha Metropolitan Medical Response System and the Douglas County Emergency Management Agency. Panelists discussed roles within their respective agencies and the importance of teamwork between agencies during times of crisis. At the conclusion of the panel discussion, conference attendees participated in three small group sessions to discuss specific emergency preparedness topics and activities including, Legislation, Regulations and Strategies Promoting a Coordinated LEND Response; LEND Assistance to Local Community First Responders; and Getting Families Ready for Emergencies. Participants will continue working in their respective groups over the next few months and will share results of their work in March of 2007.

After lunch, the group participated in A Workshop for Personal and Organizational Growth, presented by Renee Schulz, Performance Consultant from the Sioux Valley USD Medical Center. Prior to the conference, attendees completed the Bar-On EQi assessment online, and were able to participate in a group discussion of emotional intelligence during the conference. Some of the topics covered included self awareness, independence, empathy, social responsibility, stress tolerance and flexibility as they relate to leadership.

During the afternoon session, Crystal Pariseau spoke to the group about the role of LEND within the AUCD, the history of these programs, and trainee opportunities within both of these networks.

The Midwest LEND Consortium will convene again on February 5, 2007 for an Internet Protocol (IP) video seminar on Federal Disability Policy and Legislative Advocacy issues with Kim Musheno, Legislative Liaison for AUCD.



More than 40 trainees and faculty from five LEND programs gathered in Omaha, NE, for the 2006 Midwest LEND Consortium.

NETWORK NEWS

Register for the 2007 Disability Policy Seminar

March 4-6, Hyatt Regency Washington DC Hotel

Attend the special Autism Spectrum Disorders and Related Developmental Disabilities Workshop to learn about how new autism legislation will affect you.

www.aucd.org

Autism: From Research to Practice Conference held in New York

Jenny Overeynder, Strong Center LEND

Two programs of the Strong Center for Developmental Disabilities UCEDD in Rochester, New York recently sponsored a conference on Autism that attracted an audience of over 400 people.

The LEND program and the Andrew J. Kirch Developmental Services Center, together with two other programs from the University of Rochester School of Medicine and Dentistry, organized the annual Andrew J. Kirch conference on October 31, 2006.

Autism: From Research to Practice, updated the community on recent research findings by the various University of Rochester's programs in Autism. Practical implications were discussed as well. The keynote speaker was Dr. Marshalyn Yeargin-Allsopp, Fifth Annual Kirch Visiting Professor, and Chief, Developmental Disabilities Surveillance and Research Branch, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention. Her topic was: "Autism: Is there an epidemic?"

In addition, presentations were delivered on Diet and Nutrition in Children with Autism, Early Intensive Behavioral Intervention, Nonverbal Communication in Autism, and Psychopharmacology and Autism: Do medications have a role in treating challenging behaviors associated with Autism.

Excerpts of the presentations will be posted on the SCDD website: www.stronghealth.com/services/childrens/patientcare/devdisabilities.

Genetics is Relevant Now: Nurses' Views and Patient Stories

Cincinnati Children's Hospital Medical Center: Carol Hetteberg, MSN, CNS, Jean F. Jenkins, PhD, RN, FAAN, Erin K. Harvey, MS, CGC, Cynthia A. Prows, MSN, CNS

This program includes audio clips from genetics nursing experts and from patients to illustrate current genetics applications in nursing practice. Content addresses the relevance of genetics in infectious disease, oncology nursing, and common disease. NCHPEG and the Department of Nursing at the University of Cincinnati developed this Web-based educational program, available at www.gepn.cchmc.org, or go to www.nchpeg.org and choose Genetics is Relevant from the drop down menu labeled "Selected Health Disciplines."

2006 Chronic Illness and Disability/Transition Conference

Albert C. Hergenroeder, MD, Director, Baylor College of Medicine LEAH

Baylor College of Medicine LEAH Program sponsored the Chronic Illness and Disability/Transition Conference on November 2 – 3, 2006 in Houston, Texas. The conference was a success, attended by 127 participants from 7 states. 100% of the attendees responding said they will recommend this conference to a colleague. The goals and objectives for the conference were met with the overall conference speaker ratings exceeding expectations. Particular highlights included Beth Sufian, JD, legal issues and transition; Roberta Anding, RD, (Baylor College of Medicine LEAH program), weight control in hypomobility disorders; breakout sessions led by family members on practical advice regarding family supports; Patience White, MD, Transition from Pediatric to Adult-Based Care in the US, an Overview; Daniel Armstrong, PhD, (University of Miami, LEND); Craig Becker, MSSW, (University of Wisconsin, PPC) discussing transition programs; Dr. Miriam Kaufman, MD, (University of Toronto) discussing chronic illness and sexuality; Colleen Horton, MPAFF, (Public Policy Center for Disability Studies, University of Texas in Austin), legislative issues; and politics and advocacy with State Representative Scott Hochberg, Lex Frieden, MA, (National Council on Disability), and Justin Ryner, JD, (Advocacy, Inc.). Next year's conference will be held in November 2007; possible topics include learning issues in the transition with Patty Hackett from Family Voices discussing family perspectives, mental health, and the legal issues in transition. For more information on the 2007 conference, contact Tamara Greiner at tgreiner@bcm.tmc.edu.

NETWORK NEWS

Youth Consumer Leadership Presentation at VA LEND

Janet Willis, Training Director, Anne Mecham, Youth Consumer

Anne Mecham is a Youth Consumer at the VA LEND and was a guest speaker for their LEND Leadership Seminar on November 16, 2006. Anne presented as part of a panel of self-advocates from the community who discussed leadership, self-advocacy, and what LEND trainees need to know to make a difference for people with disabilities. Printed below is an excerpt from Anne's presentation.



Anne Mecham

I'm Anne Meacham. I'm 26 years old. I work as a Courtesy Clerk for Ukrops. I'm happy to be here to talk to you about leadership with you.

I see myself as a leader and think it is important for me to be an advocate for myself and for people with Down Syndrome. My mom inspires me to make good choices in my life.

I first advocated in middle school when I spoke before a committee of the General Assembly. They were discussing funding programs for people with disabilities, and I went with a group of students and teachers and parents. I am currently on the Board of Directors of the Down Syndrome Association of Greater Richmond. I am the first self advocate on the board. It makes me feel great that I can help as an adult and help parents see what their children might grow up to be. They ask me a lot of questions about what I think and what I like. I write a column called "Anne's Corner" for the newsletter. They like to hear about my life as a young adult with Down Syndrome. Some of my columns have been about going to Minneapolis and Anaheim as a representative to the National Down Syndrome Congress.

I have also written about working, about dealing with the loss of a loved one, about a musical play I was in. I have written a column for the National Newsletter Headline News. I am also a leader at work, because high school classes come into the store to shop and they see me working and they talk to me and ask me questions about my job and how I like my job. I hope that inspires them to do well and get good jobs.

My most important goal as a self advocate is to keep working. Be patient, communicate better on the job, to learn how to balance work and friendships. I go to a Job Club once a month with other Henrico County workers, and I am always trying to improve my job skills.

A leader in a disability community needs to have a positive attitude. Be the best you are able to be. Be hard working and careful. Learn to ask for help when you need it. No one is an expert at everything. Practice makes perfect! And don't always jump in and do a job for some one else. Be patient with the time a person needs to get a job done for himself.

People need to be positive, upbeat, have a sense of humor, and be friendly. Communicate by listening a lot to the people you are working with. Be patient so when you ask a question you can wait for an answer. Some people need more time to think of their answer and get it out. Follow up with more questions to be sure you really understand what the other person means. Don't assume you know what their answer is.

And most important - HAVE FUN!

"A leader in a disability community needs to have a positive attitude. Be the best you are able to be. Be hard working and careful. Learn to ask for help when you need it. No one is an expert at everything. Practice makes perfect! And don't always jump in and do a job for some one else. Be patient with the time a person needs to get a job done for himself."

NETWORK NEWS

Profile on LEND Parent Advocate Trainee Sondra Williams

Nisonger LEND, Columbus, OH: Patricia Cloppert, Faculty Parent Advocate; Paula Rabidoux, Training Director

For the past five years, the Nisonger LEND program at the Ohio State University has been developing the Parent Advocate trainee position. We viewed this position as an opportunity to provide parents with additional training in advocacy, to facilitate trainees' learning from a parent's perspective, and to build capacity in our community. Previous parent advocate trainees welcomed the additional advocacy experiences provided by their participation in LEND and they provided trainees from other disciplines valuable insights into the daily issues faced by families. The Parent Advocate trainee has participated in selected academic, clinical, and community aspects of the LEND curriculum.

In the summer of 2005, we began to discuss the possibility of Sondra Williams' participation in LEND training. Sondra has been married for 20 years and is the mother of four children ranging in age from 13-19 all of whom have been



Sondra Williams

...Sondra would bring a parent perspective to LEND, but also a self-advocate's perspective as an individual with high functioning autism... she could convey her descriptions of her feelings and needs with such exactness that I could never have obtained it from a clinic or textbook... I wish everyone in the field could have the same experience because that would help people with autism a great deal...

diagnosed with Asperger Syndrome. Sondra would bring a parent perspective to LEND, but also a self-advocate's perspective as an individual with high functioning autism. We viewed Sondra's participation as a unique opportunity for both trainees and faculty to learn more about autism from an insider perspective and to gain first hand experience with accommodation. The Faculty Parent Advocate was able to incorporate several accommodations to facilitate Sondra's participation: access to a support person, written communication via e-mail only (no telephone communication), flexible scheduling, and adapted assignments.

Sondra's autism was not correctly diagnosed until 2001. She had a difficult childhood, and as an adolescent and young adult was misdiagnosed as schizophrenic and hospitalized in psychiatric institutions. Sondra's path in life has caused her much pain, but today she feels that her advocacy for people with autism spectrum disorders has resulted in enlightened attitudes and made her journey worthwhile. She is a writer, a poet, a gifted and articulate speaker, and presents on a variety of issues related to autism. Sondra is the author of the book *Reflections of Self*, and a DVD, *Define Me*, published by The Gray Center for Social Learning and Understanding (www.thegraycenter.org). She has also consulted with parents and educators and has provided helpful insights to families. Her suggestions have often promoted successful inclusion of students with autism in regular education.

The trainees from other disciplines in Sondra's class viewed her participation in LEND training as a "highlight" of their experience. Special education trainee Jake Hackett commented, "... I absolutely loved her involvement and would hang on her every word.

Sondra's articulation of her experiences was so precise that past moments of working with individuals with autism would rush back into my memory and I could clearly understand their motives for their behavior. Sondra could convey her descriptions of her feelings and needs with such exactness that I could never have obtained it from a clinic or textbook."

Part of Sondra's LEND training included clinical participation in our Autism Spectrum Disorders Clinic. In this capacity, she observed children and parents and provided her insights during team meetings and discussions. In some instances, Sondra discussed her insights directly with families after the interdisciplinary team meeting. Trainees solicited Sondra's perspective regarding certain child behaviors to enhance their understanding of autism spectrum disorders. Anke Gross, social work trainee, stated, "I can say that working together with Sondra was one of the highlights of my training experience. She gave me an insight into autism that no book or article could have done. And she helped me understand the kids and their behavior like no other person. I wish everyone in the field could have the same experience because that would help people with autism a great deal."

Sondra's yearlong participation in LEND training was viewed positively by family members, trainees, and LEND faculty. Although Sondra's situation is unique in that she is both a parent and a self-advocate, she provided us with valuable experiences and we provided her with new opportunities. We would encourage LEND programs that have not yet included self-advocates to seek opportunities to do so.

NETWORK NEWS

Oregon LEND Pediatric PT Program Receives Credentials from APTA

Katie Laubscher Named Program's First Resident

Anne Turner, PT, MS

The Oregon LEND program at Oregon Health & Science University (OHSU) has some very good news to share that we are eager to spread within the LEND community. We have recently learned that the *OHSU Pediatric Physical Therapy Residency Program*, an application that we have been working on over the last year, has been formally credentialed by the American Physical Therapy Association (APTA). This *is the first and only APTA-credentialed Pediatric PT Residency Program in the nation*. During the process, Anne Turner, PT and LEND Physical Therapy Training Coordinator, consulted closely with Directors of other APTA-credentialed PT programs in Orthopedics for help in steering through the credentialing steps and assembled a Residency Advisory Council to develop the specific pediatric content. The Residency consists of highly structured mentored clinical experience in the three venues where pediatric PT's typically work. Our program offers experience in inpatient acute pediatric care in Doernbecher Children's Hospital, outpatient pediatric care in the Child Development and Rehabilitation Center (CDRC) Clinics and the PT program, and the educationally-based pediatric setting, including Early Intervention, Early Childhood Special Education, and School Age populations. The Resident is a full-time OHSU employee at the CDRC for one year at about a three-quarter salary, and has reduced clinical productivity expectations to match. The Resident participates fully in the LEND Training Program as the Residency Program is a natural outgrowth of what PT LEND fellows have participated in for a number of years.



Katie Laubscher

The program enrolled its first Resident, Katie Laubscher, in late August even as we were still developing the program and preparing for credentialing. Katie has a DPT degree from Creighton University and is representing the new program quite well. We learned at the site visit that we were the first applicant ever for such a residency program, largely in part to the monumental start up effort and cost of the application. Our proposal to develop this program was funded through CDRC reserve funds allocated by Dr. Brian Rogers, CDRC Medical Director.

Oklahoma LEND Trainees Design Innovative Leadership Projects

Linda Wilson, Ph.D., Oklahoma LEND Training Director

The 2006-2007 Oklahoma LEND Long-Term Trainees have designed innovative leadership projects to be implemented during the spring including individual projects and one team project. Proposed project plans were presented by the Trainees to the interdisciplinary Core Faculty at the final Leadership Class session of the fall semester. Core Faculty provided feedback to the Trainees and will mentor them during the project implementation stage. Presentations on project implementation will be made by the Trainees at a formal leadership reception in May.

Individual Leadership Projects include a wide variety of focus areas: 1) Developing a web-based interdisciplinary service route for families awaiting professional services for their children (Celina Banda, Speech-Language Pathology); 2) Tracking children's issues identified by the Oklahoma Institute for Child Advocacy for their legislative advocacy agenda during the 2007 Oklahoma Legislative Session (Amanda Cash, Public Health); 3) Identifying strategies to expand the focus on sibling issues in Oklahoma (Jaime Hampton, Parent-Family Issues); 4) Examining preservice educators' knowledge and attitudes about child maltreatment and the impact of disability status on reporting behavior (Lisa Humphreys, Psychology); 5) Developing an online connection for available assistive technology related to hearing challenges (Gretchen Magee, Audiology); 6) Creating a toolkit about children with Down Syndrome to support physicians and families (Caitlin McSpadden, Physical Therapy); 7) Setting up a trainee practicum experience with the Oklahoma State Department of Human Services (Melissa Quinlan, Social Work); 8) Developing and making available through the Internet a children's book to assist children with different learning styles improve word recognition and reading comprehension (Shannon Roberson, Occupational Therapy); 9) Developing and providing a workshop for families on a parent's perspective of the Individuals with Disabilities Education Act (Sookyung Shin, Education-Special Education); and 10) Examining the best ways to convey Person First Language concepts and appropriate use to future health care professionals (Hollie Solnok, Nutrition).

The Team Leadership Project is focused on the development of a partnership with the Oklahoma Genetics Advisory Council (OGAC) with a particular emphasis on the OGAC Genetics Education Committee. In general, the Trainees propose to identify partnership priorities with the committee that relate to committee goals including providing recommendations about the following: provision of genetic education to institutions of higher learning; public awareness campaigns and education for health professionals; utilization of various educational tools; and insuring access and integration of genetic services into established systems of care.

NETWORK NEWS

Joe Caldwell, PhD Named AUCD Policy Analyst

AUCD's Legislative Affairs team is pleased to welcome back Joseph Caldwell, Ph.D. Dr. Caldwell was recently named to the position of Policy Analyst. He was previously the 2005 AUCD Policy Fellow. Dr. Caldwell brings more than seven years experience from within the AUCD network as a student, fellow, teacher, and researcher. He is the recipient of a number of student awards from the University of Illinois-Chicago, the College of Applied Health Sciences, the Association of University Centers on Disabilities (AUCD), the International Association for the Scientific Study of Intellectual Disability (IASSID), and most recently, an AAMR (AAIDD) student award. Dr. Caldwell has been published in the *Journal of Disability Policy Studies*, *Mental Retardation*, and *Mental Retardation and Developmental Disabilities Research Reviews*.

"I am thrilled to have Joe back with the Legislative Affairs team," stated Kim Musheno, Director of Legislative Affairs. "His commitment to balancing scholarly research with advocacy adds great dimension to the Legislative Affairs team." He rejoins the AUCD Central Office on February 5, 2007.



David Morrissey Named AUCD 2007 Policy Fellow

The Association of University Centers on Disabilities is pleased to announce that David Morrissey has been named as the 2007 AUCD Policy Fellow. A recent graduate of the University of Arkansas's Clinton School of Public Service, David begins his fellowship in February.

While earning his Master's degree, Morrissey worked as the lead author of *Arkansas youth with Spina Bifida: Supporting independence through transition planning*, a manuscript that was presented at the CDC and Spina Bifida Association's joint annual meeting. He served the Arkansas Disability Policy Consortium by crafting the legislative agenda, facilitating constituent focus groups, and communicating with state representative offices to complete his Clinton School Capstone Project. David participated in a 12 week internship in Vietnam during which he served grassroots disabilities organizations in creating developmental goals. He also taught grant writing workshops at Ho Chi Minh City's National University of Social Sciences and Humanities, and to the Disabled Youth Association.

"David has a clear future in advocating, organizing, and developing policies which empower, include, and consider persons with disabilities. I'm pleased to welcome David as our 2007 Policy Fellow," stated Legislative Affairs Director, Kim Musheno.



Georgina Peacock, MD, MPH Named AUCD-CDC-NCBDDD Fellow

Georgina Peacock, MD, MPH was recently selected as the AUCD-CDC Fellow to work on the CDC's *Learn the Signs. Act Early.* campaign, promoting the early identification of children with autism and developmental delays.

Georgina completed her developmental-behavioral pediatric fellowship in the LEND program at the Developmental Disabilities Center at the University of Kansas. During this time, she also earned a Masters in Public Health. Her pediatric residency training and medical degree were also completed at the University of Kansas. She completed her undergraduate degree at the University of Michigan at Ann Arbor in Cell and Molecular Biology and German.

During her pediatric fellowship, Georgina worked on projects to increase physician knowledge about a variety of topics including identification, diagnosis, and treatment of developmental delay and autism and the need for high quality, developmentally appropriate child care. This work took different forms including teaching pediatric residents in didactic sessions and in on-site teaching at child cares. She also traveled to rural sites to talk with primary care providers. Finally, she worked with parents to help them understand their children's disabilities so that they could be better advocates for their children.

Georgina also had the privilege to spend two summers working at Centro Ann Sullivan del Peru, a school for children with different abilities. This school in Lima, Peru, teaches 450 children and adults with various conditions including autism and mental retardation. Georgina helped to set up medical services for the students by providing direct care, educating Peruvian pediatric residents about disabilities, and empowering parents by teaching them about their children's medical conditions and how to advocate for good care. She continues to work with the Center through telemedicine and will be returning in late January to evaluate students and teach in an early intervention course for teachers. Centro Ann Sullivan del Peru is an international affiliate of the Schiefelbusch Lifespan Institute in Lawrence, Kansas.

Georgina will continue to work to empower and advocate for parents, medical providers and child care providers through her new position at the CDC. Through this work, she hopes to increase awareness and ultimately improve services for children with developmental disabilities.



RESOURCES

“Tips for First Responders” Updated



The popular “Tips for First Responders” – colorful, laminated 3”-by-5” tip sheets providing guidance to support individuals with disabilities during emergencies – have been updated. Originally released in 2005, “Tips for First Responders” addressed mobility impairments, mental illness, visual impairment, deafness, cognitive disabilities, and service animals. The new second edition includes additional tip sheets on autism and multiple chemical sensitivities.

To learn more or to order “Tips for First Responders,” go to <http://cdd.unm.edu/products/TipsForFirstResponders.htm>. For further questions or ordering, contact Dr. Anthony Cahill at (505)272-2990 or acahill@salud.unm.edu.

Cultural and Linguistic Policy Assessment and Guide

We are pleased to announce that the Cultural and Linguistic Competence Policy Assessment (CLCPA) and Guide are available on the NCCC’s Website. You may access these resources from our home page at <http://gucchd.georgetown.edu/nccc> or <http://www.clcpa.info>. In addition to the PDF versions, the NCCC can provide consultation to conduct self-assessment processes (on-site and via the online version).

Overview and Purpose

The Cultural Competence and Linguistic Competence Policy Assessment (CLCPA) was developed by the National Center for Cultural Competence (NCCC) at the request of the Bureau of Primary Health Care (BPHC), Health Resources and Services Administration (HRSA), U.S. Department of Health and Human Service (DHHS).

The CLCPA is intended to support health care organizations to:

- improve health care access and utilization
- enhance the quality of services within culturally diverse and underserved communities
- promote cultural and linguistic competence as essential approaches in the elimination of health disparities.

The NCCC has also developed a companion Guide for Using the Cultural and Linguistic Competence Policy Assessment Instrument that provides step-by-step instructions on how to conduct an organizational self-assessment process.

Genetics in the Practice of Speech-Language Pathology and Audiology

Speech-language pathology and audiology students, faculty, and professionals comprise the audience for a new genetics-education program on the Web: **Genetics in the Practice of Speech-Language Pathology and Audiology**. The overarching goal of the instruction is to provide practical examples of how genetics is clinically relevant for patients and families and how it may change speech-language and audiology practice.

Genetics in the Practice of Speech-Language Pathology and Audiology was developed by NCHPEG (the National Coalition for Health Professional Education in Genetics – pronounced “NITCH-peg”) in partnership with the American Speech-Language-Hearing Association, the University of Cincinnati, and the National Society of Genetic Counselors. Funding was provided by the Health Resources and Services Administration, the National Human Genome Research Institute, the Office of Rare Diseases, and the National Institute on Deafness and other Communication Disorders.

The website can be accessed at www.nchpeg.org from the homepage or from the dropdown menu labeled “Selected Health Disciplines.” For more information, contact Erin Harvey, NCHPEG project director, at ekharvey@comcast.net.

*Genetics in the Practice of
Speech-Language Pathology and Audiology*



RESOURCES

LEND Family Resources Available

Ruth Roberts, Boling Center LEND, TN; Darla Cohen, Riley Child Development Center LEND, IN

Since February 2005 two groups of MCHB-LEND faculty and staff have worked to develop the *Promising Practices in Family Mentorship Guidebook* and the *Family Discipline Competencies*. The culmination of their efforts resulted in presentations of the two products at the AUCD 2006 Annual Meeting and Conference held in Washington, DC during October and November this year. The *Promising Practices in Family Mentorship Guidebook* provides an overview and strategies for development of a Family Mentorship program designed to incorporate the life experiences and expertise of families into professional training programs. Development of the Guidebook was based upon materials submitted by LEND programs with existing family mentorship programs. The *Family Discipline Competencies* outline common curriculum goals and competencies for the discipline of Family within the LEND interdisciplinary training structure.

Currently the two workgroups have combined their forces and continue to work toward the ongoing development of "family" as an MCH discipline. Several conference calls have yielded a tentative plan of action for 2007 including the dissemination of the developed products, participation in an MCH-wide webconference and the promotion of activities that encourage and support family trainees throughout the LEND programs. Watch future issues of LENDLinks for new and exciting updates.

The *Family Discipline Competencies* and the *Promising Practices in Family Mentorship* are available at the AUCD Website www.aucd.org or can be ordered using the form below.



AUCD PUBLICATION ORDER FORM

PROMISING PRACTICES IN FAMILY MENTORSHIP: A GUIDEBOOK FOR MCHB-LEND PROGRAMS

Note: One (1) complimentary copy of this 55-page, spiral-bound publication has been disseminated to every LEND, LEAH and PPC. Use this form to order additional copies.

LEND FAMILY DISCIPLINE COMPETENCIES

Note: One (1) complimentary copy of this 55-page, spiral-bound publication has been disseminated to every LEND, LEAH and PPC. Use this form to order additional copies.

Order	# Copies	Rate	Total Cost
<i>Promising Practices in Family Mentorship</i>		@ \$15.00 per piece	
<i>Family Discipline Competencies</i>		@ \$1.00 per piece	
Shipping		@ \$1.00 per piece	
		Order Total	

PLEASE MAKE CHECK PAYABLE TO:

AUCD, 1010 Wayne Avenue, Suite 920, Silver Spring, MD 20910

MAIL TO :

AUCD, 1010 Wayne Avenue, Suite 920, Silver Spring, MD 20910 Attn: Danielle James

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Name: _____

Organization: _____

Address: _____

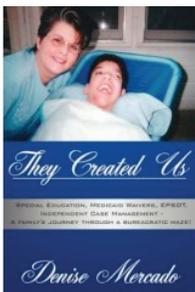
City, State, Zip: _____

Phone with area code: _____

RESOURCES

They Created Us

Denise Mercado, Team Daniel, LLC www.teamdaniel.info



They Created Us is a family's journey through the disability world that begins with their second son's encounter with Hflu meningitis at six months of age. Through their journey, you will learn the complexities of the bureaucracy along with strategies to maneuver through a sometimes unresponsive system. Special Education, Medicaid Waivers, EPSDT, and Independent Case Management are all part of a family's world when their child experiences disabilities. This family's journey uncovers injustices and allows opportunity for basic rights to be realized throughout systems that were put in place to help children with disabilities.

Written by a 1993 North Carolina Partners in Policymaking graduate, the author created this book about her family's journey through the disability world. The training provided through the Partners in Policymaking program was pivotal in her ability to access services for her son and promote change for others.

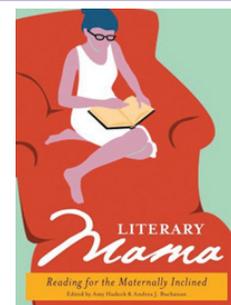
The book can be purchased through the author's personal website at www.teamdaniel.info and is also available at www.barnesandnoble.com and www.amazon.com. It is anticipated to be on the shelves of a bookstore near you in Spring 2007.

New On-line Monthly Column "Special Needs Mama"

<http://www.literarymama.com/columns/specialneedsmama/>

The goal of the column is to encourage the dialogue across camps, between special needs mamas and all mamas and dads. Literary Mama, historically, has been focused on mothers of typical kids. The author hopes this column will help to expand the conversation to other mamas, and be inclusive in its discourse.

Vicki Forman teaches creative writing at the University of Southern California. Her work has been nominated for a Pushcart and has appeared in *Seneca Review*, and *Santa Monica Review*, plus the anthologies *This Day: Diaries from American Women*, *The Spirit of Pregnancy: An Interactive Anthology for Your Journey to Motherhood*, and *Literary Mama: Reading for the Maternally Inclined*. She lives in Southern California with her husband and two children, one of whom has multiple disabilities.



NYSABA 16th Annual Conference

Excerpted from the NYSABA Newsletter, Winter 2007

Daniel W. Mruzek, Ph.D., BCBA, NY Strong Center

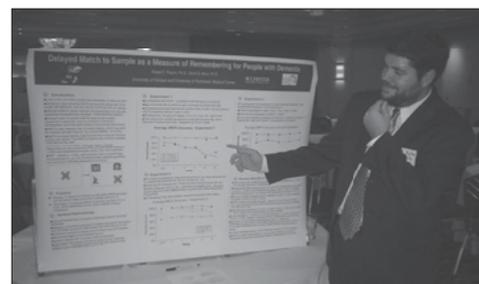
The 16th annual NYSABA conference held November 2-3 proved to be a welcome opportunity to visit with friends, catch up on new developments in the field, and get inspired by colleagues, families and consumers advocating for effective interventions and services. Here, I wish to share events that were among my personal "conference highlights."

In an invited address, Dr. Raymond G. Romanczyk of the Institute for Child Development offered a stirring address that bluntly challenged prevailing assumptions that drive the quality and funding of intervention services for children with autism and other developmental disabilities. Using classic psychological studies of perceptual biases, a brief reminder of the power of the empirical method, and humorous examples, Dr. Romanczyk laid out a systematic argument as to why science should be employed as the guide for educational and intervention services. And speaking of science, he provided a brief but compelling review of the growing body of controlled research indicating the effectiveness of applied behavior analytic intervention.

Poster sessions are usually one of my favorite parts of NYSABA conferences, and this year was no exception. Presenters ranged from students to seasoned researchers from across New York. Topics included social stories, autism and family functioning, analysis of the effectiveness of an FM system for a preschooler with autism, and use of Picture Exchange to decrease challenging behavior in a teenager with autism.

I have particular admiration for the students at the conference who put their research in the public eye for the first time. I hope you found encouragement and support from your colleagues around the state! I wish to point out one other presentation that not only informed but also inspired: A paper presented by Andrew Barsky on using video modeling to teach social skills in a child with autism. The methodological rigor and social significance of this multiple baseline study was particularly striking when one considers that Mr. Barsky accomplished this project while still in high school! Well done, sir, and we expect great things in the years to come. The future of the science of behavior is indeed bright!

I encourage NYSABA members far and wide to make plans now to participate in the 2007 NYSABA conference. We are enriched by your presence!



At the 2006 NYSABA Conference poster session, Dr. Robert Peyton, a postdoctoral fellow at the University of Rochester Medical Center, presents his poster detailing his research on using match-to-sample tasks as a measurement of dementia in the elderly.

TRAINEE CORNER

News from the Virtual Trainee

A Brief Summary of Upcoming Opportunities for Involvement

Rene Jamison-2006-2007 Virtual Trainee, Developmental Disabilities Center-Kansas LEND

This year has flown by with many opportunities for learning and leadership through the virtual trainee position, AUCD network, and my LEND traineeship. I hope that other trainees have taken advantage of the incredible opportunities we are afforded through our experiences as trainees in this network. It was great to meet fellow trainees while attending the AUCD Annual Meeting and Conference in Washington DC and I look forward to seeing more trainees at the Disability Policy Seminar in March. As the virtual trainee, my goal is to increase trainee involvement in the network and links across sites. Here's a brief summary of my plans for upcoming opportunities for trainee involvement.

Trainee Liaison Between the VT and Your Site

- Encourage active involvement in the AUCD network at your UCEDD or LEND
 - Trainee linkage opportunities
 - Enhance leadership skills

2007 Disability Policy Seminar: New Congress, New Opportunities

- March 4-6, 2007 in Washington DC
- Create connections among trainees present

Trainee Research Forum

- Share your research or projects with other trainees
- Generate ideas for projects

Look for my emails regarding these upcoming opportunities for involvement and professional development. Contact me with other ideas at rjamison@kumc.edu.



Virtual Trainee Rene Jamison interviews AUCD 2006 Annual Meeting attendees.



Trainees discuss their training experiences at the AUCD 2006 Annual Meeting.



ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES

RESEARCH, EDUCATION, SERVICE

LENDLinks

Editor

Crystal Pariseau, AUCD LEND Coordinator, cpariseau@aucd.org.

Submissions

Items of interest to LEND programs may be submitted for consideration to cpariseau@aucd.org. Items should be no longer than 250 words. Electronic copies of pictures are encouraged.

LENDLinks is published by the Association of University Centers on Disabilities (AUCD), 1010 Wayne Ave., Suite 920, Silver Spring, MD, 20910 and is supported in part by HRSA's Maternal Child Health Bureau (MCHB).

Current and back issues of LEND Links can be found on the AUCD website at: <http://www.aucd.org/LEND/newsletter.htm>.

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HRSA Releases New Chartbook on Rural Health

The Health and Well-Being of Children in Rural Areas: A Portrait of the Nation 2005, based on the National Survey of Children's Health, indicates that children in urban and rural areas are reported to be equally healthy, with about 84 percent in both groups reported in excellent or very good health. But children living outside urban areas are less likely to be breastfed and more likely to live in households with a smoker, the report says.

To view or download the chartbook, visit <http://www.nschdata.org> to visit the Data Resource Center for the National Survey of Children's Health home page and click on the chartbook icon.

The Data Resource Center features an easy-to-use interactive data query that allows users to search, view and compare NSCH results at state, regional and national levels, stratified by selected demographic characteristics including age, race, household income, insurance type, and special health care needs status.

