



News from MCHB

Denise Sofka and Madhavi Reddy
MCHB LEND Project Officers

Congratulations on another successful **LEND Directors' Meeting** at AMCHP! It was a pleasure to see the 35 LEND programs represented at the meeting. We also are excited to see that the **Social Work Discipline Meeting** has produced workgroups on the issues of LEND social work competencies, technology and the strategic positioning of social work in LEND. We look forward to partnering with these workgroups on upcoming endeavors.

We are pleased to announce that the **MCH Library** has released a new knowledge path edition that offers a selection of current, high-quality resources about caring for children and adolescents with special health care needs. This knowledge path for health professionals, policymakers, program administrators, and families includes information on (and links to) websites, electronic and print publications, databases, and online discussion groups. Separate sections list resources on specific aspects of care and development such as adolescent transition, advocacy, financing, and screening. This knowledge path is available at http://www.mchlibrary.info/KnowledgePaths/kp_CSHCN.html . Knowledge paths on other maternal and child health topics are available (See <http://mchlibrary.info/KnowledgePaths/index.html>). The MCH Library welcomes your comments and help in disseminating this information to the MCH community.

On July 10-12, 2006, the fourth annual **Translating Research Into Practice and Policy (TRIPP) conference** will be held at the Omni Shoreham Hotel in Washington, DC. The conference is co-sponsored by the Agency for Healthcare Research and Quality (AHRQ) and the National Cancer Institute (NCI), US Department of Health and Human Services. Conference highlights will include strategies and tools for designing interventions to reach and influence different audiences, to promote change in different settings where evidence-based practices might be implemented, and to discuss challenges in knowledge transfer and research implementation. Please visit <http://www.epc3.net/TRIPP06/conference/index.html> to find more information about the upcoming conference, including conference objectives, who should attend, the preliminary agenda, how to register for the conference, as well as hotel information. Please return to the website periodically for updates on the

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LEND Program Highlights

MCH Training Resource Center

The MCH Training Program has funded a new Maternal and Child Health Training Resource Center at Health Services Research, Inc. (HSR), a Washington, DC, based policy research and consulting firm. The purpose of the Resource Center is to provide expert technical support to help the MCH Training Branch achieve the goals of and meet the challenges associated with implementation of the National MCH Training Plan. Activities of the Resource Center will focus on the areas of data analysis, information management, and collaboration and strategic partnership development. While the Center will not provide technical assistance directly to individual MCH Training Program grantees, the work of the Center will support the goals of the grantees and provide resources that directly assist the work of the grantees.

Contacts at the MCH Training Resource Center are:

Judith Gallagher, Project Director at (202) 828-5100 (jgallagher@hsrnet.com)

Anita Farel, Associate Project Director at (919) 966-5983 (anita_farel@unc.edu)

Sheryl Mathis, Project Manager at (202) 828-5100 (smathis@hsrnet.com)

Specific functions of the Resource Center include the following:

- Supporting and improving data analysis, information management, and program reporting to monitor the impact of the strategic plan
- Improving program reach and coordination by fostering greater linkages and partnerships with and among the Training Program and its grantees, including ways to share and disseminate training materials
- Facilitating strategic plan implementation through information sharing by providing technical expertise and logistical support for grantee meetings, special-interest groups meetings, and the development of issue papers
- Assisting the MCH Training Program in developing and tracking strategic partnerships with national organizations, foundations, and Federal agencies. ■

Health Systems Research, Inc. (HSR): a Washington DC based policy research and consulting firm was awarded the contract to operate the national Resource Center for MCH Training.

DDC Provides Opportunity to Practice Cultural Competence & Collaboration on Interdisciplinary Leadership Projects on Rural Reservations

Vicki Miller, LSCW and Matthew Reese, PhD

Developmental Disabilities Center LEND, University of Kansas Medical Center

The Potawatomie and Kickapoo Reservations north of the Kansas capital of Topeka have entered into a collaborative relationship with the Developmental Disabilities Center at the University of Kansas Medical Center. One of our LEND social work students, **Chandra Thompson**, developed a program for maintaining healthy lifestyles and spent the summer on the



center to meet the needs of the entire county. This affiliation has provided a valuable opportunity for our students to experience a unique culture and consider different funding sources for health care systems for children. ■

Kickapoo reservations sharing her program with Native American children. This fall and spring we have taken interdisciplinary teams of faculty and LEND trainees to the reservation to do Title V special child clinics and health screenings for children with special health care needs. This summer another of our psychology LEND trainees, **Heather Hunter**, will be comparing two weight management programs on the reservations to determine culture as a variable that may impact the effectiveness of these programs. The Potawatomie Reservation will be opening a new health care center in the fall and is planning a new child care

LEND Program Highlights

Eldon Schulz: New LEND Director at Partners for Inclusive Communities, AR

David Deere, Training Director
Partners for Inclusive Communities, AR LEND

With the departure of **Mark Swanson**, Partners for Inclusive Communities has a new director, **Eldon Schulz**. Dr. Schulz is the Section Chief for Developmental-Behavioral and Rehabilitative Pediatrics in the Department of Pediatrics at UAMS, where he is the inaugural recipient of the Rockefeller Chair for Children with Special Needs. He did his undergraduate work at the University of Idaho and went on to medical school at the University of South Dakota. He completed his internship and residency at the University of California at San Diego and a fellowship at University of Massachusetts. Upon completion of his fellowship, Dr. Schulz served as Chief of Exceptional Family Member Service for the US Army in Heidelberg, Germany.



Eldon
Schulz,
MD

Dr. Schulz is the medical director for several programs, including Easter Seals Children's Rehabilitation Program, Rehabilitation Services (Occupational and Physical Therapy) at Arkansas Children's Hospital, and Arkansas Division of Developmental Disabilities Services, where he is responsible for medical services provided to 10,000 children with developmental disabilities in the state of Arkansas. For 12 years he was the medical director of the Dennis Developmental Center, a clinical program within the Department of Pediatrics that evaluates more than 5,000 children per year for developmental disabilities and is the primary diagnostic clinic for children with developmental disorders in the state. He has developed a state-wide developmental and rehabilitative clinical outreach program as well as the state-wide Foster Care Evaluation Program serving high-risk children in rural locations. He was the co-principal investigator for the state's recently completed Medical Home project.

His clinical interests include ADHD, psychopharmacology, autism, Down syndrome, traumatic brain injury, and developmental disabilities. His research interests are ADHD and associated psychopharmacology, TBI outcomes, secondary conditions in people with disabilities, and Medical Home for Special Needs Children. In his spare time, Dr. Schulz enjoys cooking and micro brewing. ■

CNMC Commencement Ceremonies

Monica Lester, MSW
CNMC, Washington, DC LEND

The DC LEND Program at the Children's National Medical Center (CNMC) would like to thank our 2005-2006 LEND graduates. We would like to congratulate them for all of the hard work and dedication they contributed during the program year. The LEND graduates have produced exemplary projects/presentations as a requirement of the program. Each graduate had the opportunity to present to colleagues/peers and faculty members as a requirement of the program during this year. Our celebration was on April 26, 2006, in the Children's Research Atrium at CNMC which included faculty members, discipline coordinators and a

host of friends and family of the LEND graduates. We had the pleasure of **George Jesien, PhD**, Executive Director of AUCD, to serve as the keynote speaker for the ceremony. Our LEND program is in its second year at CNMC and we look forward to an exciting new program year to begin in September 2005. ■



CNMC
'Class of
2006'
& their
mentors

LEND Program Highlights

LEND Legislative Update

Kim Musheno
AUCD

[AUCD Board President Testifies Before Congress](#)

On March 30, AUCD Board President **Lu Zeph** (Maine UCEDD) provided excellent testimony on UCEDD and LEND funding before the House subcommittee that holds responsibility for deciding annual appropriations for AUCD programs. Lu was joined by a parent of a child receiving services at one of AUCD's UCEDD/LEND programs, **Victoria Sulerzyski**, whose daughter **Abigail** is a child with multiple developmental disabilities. The Sulerzyski family receives services from the Kennedy Krieger Institute at The Johns Hopkins University in Maryland. Labor-HHS-ED Subcommittee Chairman Ralph Regula (R-OH) asked both Lu and Victoria probing questions about the LEND and UCEDD programs. Written testimony on behalf of the UCEDD and LEND programs was submitted for the record.

[Title V Block Grant](#)

AUCD joined several LEND Directors on visits to appropriators to talk about the LEND programs and funding needs. AUCD

supports an overall increase of \$31 million for the MCH Block Grant to bring it up to a total funding amount of \$724 million in FY 2007. Within the block grant, AUCD is urging Congress to appropriate \$22,667,664 (an increase of \$4 million) within the Special Projects of Regional and National Significance (SPRANS) set-aside for the LEND program. Additional funding will enhance the capacity of LEND programs to train professionals in the interdisciplinary care and treatment of children with special health care needs and their families and to address critical unmet needs of children with autism, down syndrome, and genetic disorders. Twenty-five bipartisan Members of Congress have signed on to a Dear Colleague letter in support of

funding the UCEDD and LEND programs at the highest possible level.

[AUCD Provides Autism Briefing to Senate HELP Committee](#)

On April 18, 2006, at the request of Senate Health, Education, Labor and Pensions (HELP) Committee staff, AUCD provided a briefing on issues related to early detection and intervention for children with Autism. Committee staff are working on the reauthorization language for the Children's Health Act of 2000 (42 U.S.C. 247b-4b). They were interested in learning more about programs targeted at two to five year-olds prior to entry into kindergarten, current procedures for early identification and screening, as well as models/tools used to screen for developmental delays or autism in this age group.

Dr. Rebecca Landa, Director of the REACH Research at Kennedy Krieger Institute (KKI), **James Mancini**, Speech-Language Pathologist and REACH Program researcher at KKI, and **Dr. John Constantino** from Washington University in St. Louis helped brief staff members. AUCD Executive

Director **George Jesien, PhD**, provided an overview of the LEND programs and their role in providing interdisciplinary leadership development and direct services in the area of autism. He shared information gained from a recent survey of the LENDS showing increases in the number of referrals the LEND programs have received over the past decade and the critical need for trained professionals who will provide assessment and intervention services throughout the country. Dr. Jesien also discussed how autism is the perfect example of a condition that requires an interdisciplinary approach to assessment and intervention and emphasized



Victoria Sulerzyski (KKI) and AUCD Board President Lu Zeph (ME) testify before House Appropriations subcommittee

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LEND Program Highlights

Pediatric Assessment Center (PAC) Collaborative Project

John F. McLaughlin, MD

Center on Human Development & Disability, University of Washington LEND

Trainees and faculty at the University of Washington (UW) LEND Program are using their expertise in neurodevelopmental disabilities to inform the treatment of children with serious emotional and behavioral problems. The Pediatric Assessment Center (PAC) is a collaborative project between UW LEND, Center on Human Development and Disability (CHDD), and Seattle Children's Home (SCH), a community child mental health agency. The PAC is a popular training experience with trainees and enhances the skills of SCH staff and LEND faculty.

In response to concerns by SCH staff that many clients were not responding to intensive mental health services, the PAC was established as a community demonstration project bringing mental health and developmental disabilities expertise to bear simultaneously at SCH. Evaluation was provided by UW's MCHB-funded Public Health Training Program faculty. The interdisciplinary model of assessment and treatment planning was adapted from the UW LEND training clinic. This includes a joint record review, face-to-face discussion of specific concerns by the SCH staff and LEND faculty, followed by developmental pediatrics

consultation, neuropsychology assessment, selective discipline consultations and a joint wrap-up meeting including client/family. LEND trainees participate in these consultations.

From 2002, when the PAC was founded with funding from the Bill and Melinda Gates Foundation, through March 2006, PAC members evaluated 156 children and adolescents. Approximately 35% of clients have been in long term foster care, 70% have experienced abuse/neglect, 40% have prior inpatient psychiatry admissions, and 25% have juvenile justice involvement. Assessment has resulted in new or clarified diagnoses for nearly 60 percent of clients, including neurodevelopmental disabilities, chromosomal, neurological and medical disorders. Interdisciplinary understanding and communication leads to improved management of the client's behavior. The experience is compiled and presented as a basis for identifying funding sources to study possible long term benefits or cost-savings and to explore replication.

For more information, contact <http://depts.washington.edu/lehd/>. ■

LEND Legislative Update

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that the existing infrastructure of the LEND network is positioned to be able to make a national impact on the need for trained and qualified professionals in this area.

Dr. Jesien also provided information regarding the CDC's successful National Center on Birth Defects and Developmental Disabilities (NCBDDD) national campaign called *Learn the Signs, Act Early*. The campaign has reached thousands of parents, pediatricians and health workers and will be targeted to child preschool and child care providers in the near future. AUCD staff also discussed the importance of the Part C of IDEA, the Infant and Toddlers Program, Early Head Start, and Head Start as parts of a comprehensive system for early screening and

identification.

AUCD was encouraged by the number of Hill staff in attendance. Senate offices represented by staff included Senators Enzi (R-WY), Chairman of the HELP Committee; Kennedy (D-MA), Ranking Minority Member of the committee; Dodd (D-CT); and Santorum (R-PA). AUCD invited staff to visit local LEND programs and to contact any LEND or UCEDD regarding further questions or needs for additional information about current practices or research.

To read AUCD's L-HHS testimony or read more about the autism briefing, visit the Legislative Affairs section of www.aucd.org. ■

LEND Program Highlights

Midwest LEND Video Conference: Federal Disability Policy and Legislative Advocacy

Suzanne Pearson, Iowa LEND

Faculty/staff and trainees from the Iowa, Nebraska and South Dakota LEND programs met for a second time this year on Friday March 31, 2006, for a video conference on Federal Disability Policy and Legislative Advocacy. **Kim Musheno**, Director of Legislative Affairs at AUCD, was the featured speaker for this two-hour conference. Objectives for the session were to:

- Relate practice issues to disability policy, legislative action, and regulations
- Understand national and state policy process interface with legislative action
- Identify advocacy strategies that promote current disability legislation

Kim provided a number of handouts and a PowerPoint presentation for attendees and encouraged participants to come to the session with questions on the material in order to facilitate discussion. As an introduction to the session, Kim spoke about her professional leadership journey, which resulted in her interest in legislative advocacy activities.

Major topics covered during the presentation included the evolution of a bill prior to being signed into law; how to advocate effectively with legislators; and the role of various committees, including budget, appropriations, and authorizing committees. Kim provided several “real life” examples of individuals with disabilities who made their stories public, and stressed the power of the personal story when talking with legislators.

Kim also talked to the group about the Family Opportunity Act, funding history of the LEND program, the Special

Projects of Regional and National Significance (SPRANS), and the 2007 LEND proposal for the MCH Block Grant.

In closing, Kim encouraged all of us to get involved in legislative/policy activities. She stressed that clinicians and other providers are immersed in the issues and are an important communication link in providing information to policy makers.

“We [AUCD] represent you – the experts,” Kim said. “We need you to bring forward the issues that might be resolved with federal legislative action.”

Summary comments from faculty and trainees included:

“I gained an appreciation of the complexity of political action and advocacy and developed a desire to become involved,” said one trainee.

“This was a great opportunity for trainees and faculty to connect with the front line people working within our political system with a focus on developmental disabilities issues.”

Another participant wrote, “Kim did a great job of describing the legislative process on such a large scale.”

Several individuals commented that information about the Family Opportunity Act helped them to better understand this important piece of legislation.

The following trainee quote made it clear that we had accomplished one of our most important priorities for this seminar: “I gained an appreciation of the complexity of political action and advocacy and developed a desire to become involved.”

The Midwest LEND group plans to make the Spring video conference an annual event and hopes to expand it to other programs in the LEND network. ■

LEND Program Highlights

Diagnosis and Treatment of Autism in Infants and Toddlers Advances at AECOM's Rose F. Kennedy Center

RELATE: Rehabilitation, Evaluation & Learning for Autistic Infants & Toddlers at Einstein

An advanced program for diagnosing and treating infants and toddlers with autism has been established at the Children's Evaluation and Rehabilitation Center (CERC) at the Albert Einstein College of Medicine of Yeshiva University. The program, known as RELATE (Rehabilitation, Evaluation and Learning for Autistic Infants and Toddlers at Einstein), provides comprehensive services for the youngest patients. The program offers in-depth multidisciplinary diagnostic evaluation and treatment for children, from birth to preschool, with language, social, or behavioral difficulties including autism and related disorders.

Following the nationwide trend, over the past decade the number of children referred with social and behavioral difficulties associated with autism has doubled at CERC. The RELATE program was established in order to bring state of the art diagnostic and treatment programs to the Bronx and the surrounding tri-state community. The program utilizes "gold standard" diagnostic tests and a

multidisciplinary approach to assess each child's ability to communicate, engage, and interact socially. The team includes developmental pediatricians, psychologists, speech and language pathologists, special educators, social workers, audiologists, and occupational and physical therapists. Services are provided in English and Spanish. Once a diagnosis is made, a comprehensive intervention plan is put in place. One of the main services provided is helping parents obtain an appropriate therapeutic program, either at CERC, in the home, or in the child's school district. Recommendations for appropriate additional medical work-up also are coordinated through the program including Genetics, Neurology, Gastroenterology, Nutrition, Psychiatry, and sleep studies.

For more information about the RELATE program, contact **Dr. Lisa Shulman**, a board-certified Neurodevelopmental and Developmental/Behavioral Pediatrician, and Director of the RELATE program at CERC at (718) 430-3901. ■

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conference agenda. No registration fee is required for this year's conference.

In May, Madhavi Reddy will be visiting the LEND programs at the University of Pittsburgh and West Virginia University as a member of the review team from **HRSA's Office of Performance Review (OPR)**. Each year, HRSA conducts approximately 500 performance reviews to assure that the more than 3,000 organizations receiving grant or cooperative agreement funding from HRSA are successfully accomplishing their program purposes.

A performance review is a collaborative effort between HRSA and the grantee. It includes:

- Selection of Performance Review Measures
- Analysis of performance in relation to the selected

Performance Review Measures

- Creation of a Performance Report, which includes Performance Improvement Options
- Development of an Action Plan, which includes Performance Improvement Actions to be completed by the grantee on each Performance Review Measure.

An OPR visit also is planned for the University of Iowa LEND program later in the year.

As MCHB plans future MCH Training **MCHCOM.COM webcasts**, please feel free to send your suggestions and/or comments to **Madhavi Reddy** at mreddy@hrsa.gov. Archived MCH Training MCHCOM.COM webcasts are available at <http://www.mchcom.com> and are available on the MCH Training Program Web site at <http://www.mchb.hrsa.gov/training>. We'd love to hear your suggestions! ■

LEND Program Highlights

LEND Trainees Attend National Autism Conference

Peter A. Blasco, MD
Director, Oregon LEND Training Program

In March, speech-language pathology LEND trainees **Angela Boyer** and **Brandon Buckendorf** were sponsored by the LEND program to attend the Spectrum of Developmental Disabilities XXVIII: “Autism: from Kanner to Current” conference, sponsored by Johns Hopkins University and the Kennedy Fellows Association of the Kennedy Krieger Institute. The conference took place in Baltimore, Maryland. The trainees wanted to share some of their experiences.

Angela Boyer:

I was granted the opportunity to attend this fantastic 3-day interdisciplinary conference. It was especially exciting to attend a conference where so many renowned autism researchers came together to lecture, outlining the most current and up-to-date information in autism research.

I was impressed by the wide scope of topics. From epidemiology to environmental influences, clinical manifestations to developmental changes and intervention, the topic of autism was thoroughly covered. Sandra Harris, PhD, presented an angle that I had never considered. Her topic was siblings of children with autism. I appreciated the stories she shared of the young siblings: fears about “catching” autism and the feeling of being overwhelmed by the idea that some day they may be the sole caretaker for their sibling. In addition, she discussed ways that families can support the siblings: setting aside special one-on-one time, talking about their fears, enrolling them in a support group, or seeking play skill training in the hope of increasing productive inter-sibling relationships.

Brandon Buckendorf:

My experience at the 2006 “Kanner to Current” autism conference was wonderful. Not only had I never been to a conference of this magnitude, but I had never been exposed to a comprehensive history, differential diagnosis, and treatment symposium on autism. I was impressed with the quality of presenters and the wealth of knowledge each of them contributed to this topic.

I appreciated the video clip shown of Dr. Kanner. The video depicted a brilliant man who sparked the world’s interest in autism. He was well into his 80’s but still contributing to advancements in the area of autism. He humbly admitted that he was not the first to observe a group of symptoms later to be called autism and that he was so proud at how far awareness and research in autism had advanced.

We want to thank our LEND program for the opportunity to attend this invaluable conference. We both look forward to applying this newly gained knowledge in clinical practice. ■

“We want to thank our LEND program for the opportunity to attend this invaluable conference. We both look forward to applying this newly gained knowledge in clinical practice.”

Editorial Comment:

In 1978 I went to my very first national professional conference, the annual meeting of the AACPD held in Toronto. I was a LEND fellow in developmental pediatrics at the Kennedy Institute in Baltimore. I can still picture the hotel where I stayed – a cheap (sleazy) affair about a mile walk from the conference hotel. (LEND directors were not so generous with their trainees back in those days.) I believe to some extent it was a career-defining event. Like Angela and Brandon, I was greatly impressed, indeed moved, by what I encountered: enormous expertise, genuine camaraderie, and deep dedication to every aspect of academic function – clinical excellence, superb teaching, and meaningful research.

This short addendum to the descriptions provided by our two LEND trainees is directed to LEND Program Directors and

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LEND Program Highlights

Utah, New Mexico & Wisconsin LENDs Link-Up for Seminar

Rita Hohlstein, MS, OTR, WI; Judith Holt, PhD, UT; Carolyn Richardson, EdD, NM

On Friday, March 24, 2006, faculty and trainees from three LEND programs, linked through the use of interactive video technology, to share an outstanding seminar on “Evidence-based Genomics.” This was led by **Jeffrey R. Botkin, M.D., M.P.H** who is a Professor of Pediatrics and Medical Ethics and Associate Vice President for Research at the University of Utah. The Utah Regional LEND and Utah’s UCEDD partners in Idaho, North Dakota, and Wyoming hosted the LEND programs from New Mexico and Wisconsin. Although this was the first link-up adding New Mexico and Wisconsin, the technology challenges were modest. There was active discussion and questions from the combined student body (44 trainees, including parents and youths with disabilities from the 6 sites and 20 faculty members) with continued discussion at each site at the conclusion of the seminar.

Students from all of the sites were excited about the opportunity to not only learn more about the topic but also to have contact with more students and faculty. An excellent comment from the NM trainees was the need to develop these types of connections among LEND programs that are student driven, facilitated, and evaluated. This hopefully could lead to a much stronger student network

and a better understanding of the AUCD network and its importance for all students.

Trainees from Utah, Idaho, North Dakota, and Wyoming were enthusiastic about being able to interact with such a diverse set of trainees. They noted that they would like to see this concept expanded over subsequent years with the possibility of small group activities and reaction papers integrated into the multi-state process about their expanded experience.

Since Wisconsin has a MCH LEND/Genetic Counseling Project, the students suggested using this technology for increased collaboration related to genetics with other LENDs, both those which have Genetics/Genetic Counseling as core disciplines and those which do not.

All three programs are planning to continue and expand these interactive seminars during the next academic year. Next year the NM LEND will take the lead for a seminar on cultural and linguistic competency and the WI LEND will take the lead for a seminar on violence and its impact on young children. We are also discussing having the UT LEND take the lead on a seminar on emergency preparedness. ■



National Conference

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Training Directors as a strong plea in support of these sorts of trainee experiences, which I believe can have a substantial impact on a trainee’s career direction. Yes, we have no money; our budgets have precious little wiggle room for educational travel. But it may be worth more than we think. For some trainees, making certain that we find a way for them to have the kind of experience described above should be one of our highest priorities. In my mind the annual AUCD meeting, the AACPD annual meeting, and the annual Spectrum course described above are top choices. Why? For two reasons: one, because the quality of these programs is always exceptional, and, two, because each conference has an incredibly strong interdisciplinary focus. –**Peter A. Blasco**

LEND Program Highlights

State Leadership Reflects Success of Oklahoma LEND Family Advocate Training

Linda Wilson, Ph.D.
Oklahoma LEND Training Director

Since the Oklahoma LEND began in 1995, the family perspective has been incorporated into interdisciplinary training activities through the leadership of **Jan Moss**, Oklahoma LEND Core Faculty in Parent-Family Issues. The impact of Jan's involvement has been significant with both interdisciplinary trainees and faculty. During the 2004-2005 program year, Jan participated in the selection of **Wanda Felty** as the first long-term trainee in Parent-Family Issues. Wanda is the parent of three children, one of whom has disabilities. During her leadership training, Wanda provided parent-family perspectives in all interdisciplinary trainee activities. Wanda was mentored throughout the year by Jan Moss as her Core Faculty Mentor. The success of LEND training for a family advocate is evidenced by the leadership Wanda has shown since completing the Oklahoma LEND Program.

Meet Wanda Felty, Family Advocate and Former Oklahoma LEND Trainee in Parent-Family Issues:

"Since finishing my LEND training, I have not stopped. The LEND experience has sparked a fire under me like I have never had before. In addition to the spark, it has empowered me to be comfortable speaking as a professional in the field of Family Issues. Of all the skills and knowledge LEND provided, it was the education that *I'm a professional* that set me on the path I am taking now. I



Wanda Felty
& Jan Moss,
OK LEND

was chosen to represent the state of Oklahoma as a Family Scholar at the AMCHP National Conference in Washington, DC.

While there, I met with Senator Coburn and staff from the offices of Senator Inhofe and Congressman Cole to discuss issues in our state affecting families who have children with special health care needs. I represented the family perspective on the TEFRA Policy Committee of the Oklahoma Health Care Authority prior to implementation of the TEFRA Program in Oklahoma. I currently serve on the Policy Advisory Committee for Persons with Developmental Disabilities through the Oklahoma Department of Human Services (ODHS). My term will expire in 2009. I also serve on the Self Directive Care Advisory Committee through the ODHS Developmental Disabilities Services Division. I organize and facilitate the "Waiting List" meeting that allows families to meet with the ODHS Director and other ODHS administrators. I chair the Human Rights Committee for Dunganvin Oklahoma, a provider agency. I am a state representative for Unlocking Autism and a Family Mentor for the Oklahoma Family Network, the Oklahoma family-to-family mentor program. I also work with the Oklahoma Family Support 360 Center Resource Team and the Oklahoma Family Support Council. I am collaborating with the current Oklahoma LEND Trainee in Parent-Family Issues in the creation of Sibshops in our state. I continue to work as the Family Advocacy Coordinator for the Oklahoma Infant Transition Program at the Children's Hospital of Oklahoma and serve on hospital committees promoting family/patient-centered care and developmental care. Last but not least, I continue to advocate for my daughter who has developmental disabilities and who is transitioning into adulthood." ■

"The LEND experience has sparked a fire under me like I have never had before."



Resources

Brighter Tomorrows: Supporting Families with Accurate Information about Down Syndrome

AUCD is thrilled to announce that the Interdisciplinary Human Development Institute (University of Kentucky UCEDD) recently released *Brighter Tomorrows*, an interactive CD designed to teach physicians how to provide families of children with Down syndrome accurate and supportive information about their child at the point of initial diagnosis. This teaching tool includes two interactive cases studies. Interactive Case 1 focuses on patient-doctor communication and information when a child is first diagnosed with Down syndrome at birth. Interactive Case 2 illuminates critical issues of diagnoses in utero, including information on types of screening and diagnostic tests available, their reliability, and risks.

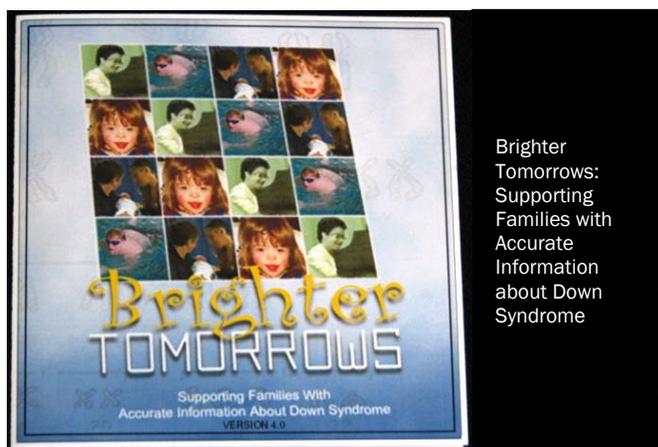
This wonderful resource is also complete with 'real-life' stories of how families were informed, as well as physicians' stories of how they were able to give the news to families in positive and supportive ways; life glimpses of individual children and young adults that cover a range of ages, activities, and accomplishments; and a resources feature.

Funded under the AUCD-NCBDDD cooperative agreement, a core group of physicians, faculty, and parents served as the project development team, and focus groups of both physicians and parents informed the direction of the CD. The project team is in the process of creating a web-based parent and family version of *Brighter Tomorrows*, which will be available in Spanish and English.

For additional information or a copy of the *Brighter Tomorrows*, please contact:

859-257-4460, or
Harold.kleinert@uky.edu or 859-257-3045. ■

Carol Lunney, PhD (Project Director) at calunney@uky.edu or
Harold Kleinert, EdD (Executive Director) at



Brighter Tomorrows: Supporting Families with Accurate Information about Down Syndrome

AUCD Branding: Logos Available for Download and Use on Your LEND Publications

AUCD has launched an initiative to encourage its member organizations to collaborate in promoting the AUCD name and logo. By including the AUCD logo and language about your relationship to the AUCD network in your online and print communications you can enhance the promotion of your own program by:

- Showing that you are linked to a larger, national network
- Demonstrating that you have a presence in Washington, DC
- Demonstrating that you have access to the experience and knowledge of a broad network of organizations doing similar work and the ability to call on those resources when needed



Tips for AUCD centers and programs to strengthen their links to AUCD, build their own name recognition and contribute to the development of the AUCD brand are posted on the website at <http://www.aucd.org/logo>, along with logos that you can download and use on your program's website, newsletters and other communications.

For more information on the AUCD branding initiative, contact Evette Mezger, emezger@aucd.org. ■

Resources

NCCC: Language Access Resources

The SIDS/ID Project of the National Center for Cultural Competence is pleased to announce a new feature on our website. We know that dealing with interpretation and translation are challenges that we all face as the linguistic diversity of our country is growing. This feature is a list of frequently asked questions about the whats, whys and hows of providing language access for the individuals and families you serve. It contains useful links to an array of resources. While it was developed for our SIDS/ID Project, the information is applicable across health and mental health programs. NCCC hopes that this will be a useful support to the field.

You can find this new feature at: <http://gucchd.georgetown.edu/nccc/languageaccess.html>. ■



Report Assembles Research on Policies Affecting Families

Twenty State Policies to Create Bright Futures for America's Children, Families and Communities assembles research on effective policies in areas that affect a family's opportunities and stability: employment, income and asset growth, health, education, and healthy family relationships. The report, published by the Center for the Study of Social Policy, is divided into two sections. The introductory section provides an overview of the challenges that states and families face in the current economy and outlines 20 policy areas that could enhance opportunities for children and families, strengthen communities, and build stronger state economies. The state policy overview section provides the following for each of the 20 policy areas: a research summary on policy effectiveness, highlights of key policy measures, and a presentation of the status of policy in each state and the District of Columbia in each of the 20 policy areas. A data source list is included. The report is available at <http://www.policymatters.us/fullreport.html>. ■

The State of Depression in America

The Depression and Bipolar Support Alliance (DBSA) is pleased to provide you with an Executive Summary of our report, *The State of Depression in America*. With the help of nationally known consumers including veteran CBS anchorman Mike Wallace, representative Patrick Kennedy, former CNN Chief Tom Johnson, and the help of leading consumer advocates including Larry Fricks, Jennifer Martin, Jana A. Spalding, MD; and the assistance of nationally recognized researchers and health care professionals including Surgeon General Richard Carmona, Ellen Frank, PhD, and Madhukar Trivedi, MD, DBSA presented a comprehensive overview of the impact and cost of depression in America today.

The full report and the accompanying video can be downloaded from our website at this location.

<http://www.dbsalliance.org/stateofdepression1.html>. ■

Resources

New CSHCN Knowledge Paths Available

New editions of MCH Library *Knowledge Paths* are now available. Recent additions include *Children with Special Health Care Needs (CSHCN)*, offering a selection of current, high-quality resources about caring for children and adolescents with special health care needs, and *Autism Spectrum Disorders (ASD)*, providing information on ASD identification and intervention.

Produced by the MCH Library, the knowledge path includes information on (and links to) Web sites, electronic and print publications, databases, and online discussion groups for health professionals, policymakers, program administrators, and families. Separate sections list resources on specific aspects of care and development such as adolescent transition, advocacy, financing, and screening. MCH Library knowledge paths on other maternal and child health topics are available at <http://www.mchlibrary.info/KnowledgePaths/index.html>. ■

Occupational Therapy Website

The Center for Development and Learning is pleased to announce its new occupational therapy informational website at www.cdl.unc.edu/occupationaltherapy. The website offers descriptive information about occupational therapy with school-aged children, presented in language easily understood by families, educators, multidisciplinary medical and allied health professionals, and other professionals and students. The website includes a description of occupational therapy, examples of typical childhood occupations, an explanation of the focus of O.T. assessments/interventions, and additional occupational therapy resources. Information reflects the Occupational Therapy Practice Standards adopted by the American Occupational Therapy Association in 2002.

We encourage others to print out website pages to use as educational handouts--formatting is in printer-friendly, single pages! It's an easy way to provide focal information about occupational therapy to trainees, interdisciplinary professionals, and families. In addition to the direct link above, the website can be accessed through the main CDL web page www.cdl.unc.edu by clicking on the "Individuals & Families" tab, scrolling down to "Resources", and then on the Resource page, scrolling down to the heading "Occupational Therapy at the Center for Development and Learning".

For more information, contact Catherine Alguire, MLA, OTR/L at the UNC LEND. ■

NADD Spring Teleconference Series

The National Association for the Dually Diagnosed (NADD) is offering its spring teleconference series.

Schedule: (all conference times are 3:00-4:00pm ET)

- May 10, 2006: The Biopsychosocial Model of Assessment
- May 16, 2006: Programming for Offenders with Mental Retardation
- May 18, 2006: Creative Therapies in Mental Health Recovery
- May 23, 2006: Aging and People with Dual Diagnoses
- May 25, 2006: Therapeutic Interactions

Registration (per session): NADD Members: \$60; non-members: \$75; students/consumers/family members: \$50.

For a brochure and online registration, visit the NADD website at www.thenadd.org. ■

Resources

Mental Retardation in Developmental Disabilities Research Reviews

Wading through numerous publications for the information you need? Switch to *Mental Retardation and Developmental Disabilities Research Reviews* (MRDD) and get the "whole picture"...

Published in Affiliation with AUCD's Developmental Disabilities Research Centers (DDRCs), MRDD is an international forum for the exchange of novel and significant information on the broad aspects of developmental disabilities. The Journal provides a focus for scientific reviews and editorial commentaries among neuroscientists, geneticists, neurodevelopmental pediatricians, and behavioral scientists interested in clinical or basic science research in aspects of brain development and function.

Each issue is thematic, edited by an expert in the chosen topic, and provides a comprehensive and diverse exploration of the critical genetic, neurobiological, and behavioral aspects of the subject.

[Volume 11 Issue 4](#) - December 2005: New Technical Approaches to Developmental Disability Research

[Volume 11 Issue 3](#) - August 2005: Neurodevelopmental Assessment of the Young Child

[Volume 11 Issue 2](#) - April 2005: Novel Therapies for Developmental Disabilities

[Volume 11 Issue 1](#) - February 2005: Neurodevelopmental Assessment of the Fetus and Young Infant

Visit <http://www3.interscience.wiley.com/cgi-bin/jhome/38853> for subscription information, sample issues, and more. ■



Successful Grassroots Health and Wellness Programs: Exploring Common Traits

Successful Grassroots Health and Wellness Programs: Exploring Common Traits discusses commonalities among successful programs in seven cities across the country that are working to help the people in those communities adopt and maintain healthier lifestyles. The report, published by the American Council for Fitness & Nutrition (ACFN), documents experiences and successes shared by more than 550 local community leaders and health and wellness professionals during a series of forums held in 2005 in Little Rock, Austin, Philadelphia, Baltimore, Chicago, Albuquerque, and Oklahoma City. Each event consisted of a facilitated panel discussion by nutrition and fitness experts, government, and large employers with local operations; presentations by leaders of innovative local programs; and a question-and-answer session. The report includes a summary of the conclusions, accompanied by supporting examples from highlighted programs. Two resources, one for community leaders and one for parents, are also provided. The resource for community leaders presents a brief description of the traits of successful programs, and the resource for parents lists four questions ACFN recommends parents ask when considering whether to involve their child in a health and wellness program. A brief description of each participating program is listed by city at the end of the document. The report is available at <http://www.acfn.org/resources/ACFN.200-02.TriumphSummary.pdf>. ■

Trainee News

LEND Trainee/UA Clinton School Graduate Student to Serve Grassroots Disabilities Organizations in Vietnam

David Morrissey, LEND Trainee

Partners for Inclusive Communities, the University of Arkansas for Medical Sciences Center on Disabilities

University of Arkansas Clinton School of Public Service inaugural class student and LEND trainee **David Morrissey** will perform a 12-week fieldwork internship in Vietnam this summer, assisting grassroots organizations that serve persons with disabilities. David will provide organizational consultation, foster collaborative networking between organizations, and prepare grant applications and outreach materials in English for advancing the good work of these organizations. David will also author an independent assessment of the situation of persons with disabilities in Vietnam based on his experience and research that will include key findings and recommendations.

David's internship has been organized by Peacework International and he will be based in Ho Chi Minh City, formerly Saigon, hosted by the Vietnam YMCA. This experience will contribute to David's Master of Public Service degree, US-Vietnam relations, and the developing role of the Clinton School of Public Service as a global resource. David is an experienced human services leader and himself a person born with a disability, Spina Bifida, facts which add to the enthusiasm of his hosts for the project.

It is estimated that over 10% of the Vietnamese live with some form of disability, a figure which does not include people with HIV/AIDS, psychiatric illness, or the general elderly population. Vietnam's grassroots "self-help

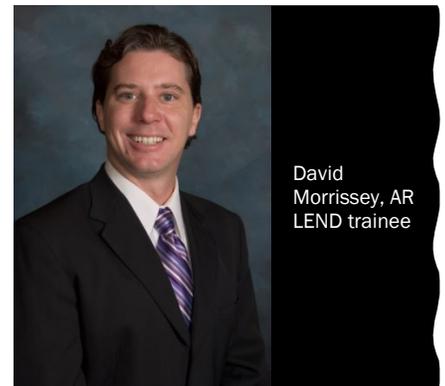
movement" is in its nascent stage, with organizations being formed by stakeholders seeking to fill gaps in available services and to provide training and advocacy. As government reforms and a national "Ordinance on Disabled

Persons" have raised awareness of the abilities to stakeholders to direct their own services, there is a need for collaboration and capacity growth at the grassroots level. David hopes to have a positive impact in this area. Because of the relationship and history between the

"It is estimated that over 10% of the Vietnamese live with some form of disability..."

United States and Vietnam, this project has profound implications which David is hoping to raise interest in and support for among his own countrymen.

David Morrissey may be contacted at dnmorrisey@clintonschool.uasys.edu. Peacework International may be contacted directly regarding donations by calling Stephen Darr: (800) 272-5519, or visiting www.peacework.org. David's participation in LEND has been at the Partners for Inclusive Communities, the University of Arkansas for Medical Sciences Center on Disabilities. The LEND Program coordinator is **David Deere**, who may be contacted at deereglend@uams.edu or by calling (501) 682-9917. ■



David
Morrissey, AR
LEND trainee

Be sure to check the trainee website for message board news, virtual trainee updates, events, and more!
www.aucd.org/aucd_trainees

Trainee News

LEND Trainee Works with Children with Special Health Care Needs in Russia

Barb Johnson, PT, Shriners Hospital, Salt Lake City, UT and Former Utah LEND Trainee

Amy Shuckra, PT, is the physical therapy trainee in the Utah LEND program. Amy has worked with the Firefly Children's Network for the past five years on a community project to de-institutionalize children with special health care needs living in orphanages in Kazan, Tatarstan, Russia. Her work with Firefly Children's Network has centered on preventing abandonment of children with developmental disabilities and the development of a multi-disciplinary program in Tatarstan, Russia to support these children and their families. Firefly has been successful in gaining community support, providing community evaluation, and providing educational training to medical and educational personnel. Firefly hopes to place children in a foster family by spring 2007. Amy's capstone project was to present reviews of the literature on developmental outcomes of institutionalization, benefits of removing children from orphanages, and building the necessary community support to facilitate this process. Amy discussed the use of congregate care facilities in the United States in comparison to the orphanages in Russia. The following link contains more information on Firefly Children's Network www.fireflykids.org. ■



Amy Shuckra works with a child in Russia



Missouri LEND Trainee Receives Honors

Kay Conklin
University of Missouri-Columbia LEND

Megan Madden, currently an occupational therapy graduate student in the University of Missouri's LEND program was recently selected as a member of the elite 2006 Class of Mizzou '39.

The 39 recipients were selected based on academic achievement, leadership, and service to Mizzou and the community. A committee comprised of faculty, staff, and alumni reviewed more than 100 applications. In addition to detailing their activities and involvement, applicants were asked to name one faculty/staff member who has made an impact on their life at Mizzou. Megan selected **Lea Ann Brittain**, the occupational therapy faculty for the LEND program.

Recipients were honored at the Campus Founders' Celebration on February 9 and at an award banquet on February 10, both held in the Reynolds Alumni Center. Additionally, the 39 seniors were honored once again at half-time of the Missouri-Texas A&M men's basketball game on February 21.

The award program was organized by the MU Alumni Association Student Board in the spirit of service modeled by the University founders. The organization's mission is to "safeguard the traditions of our Alma Mater, to foster a sense of pride within the Mizzou community, and to serve as the governing board for all True Tigers." The Class of '39 represents the year 1839 when the University was founded. This is an annual award. ■

Trainee News

Are you looking for a National leadership opportunity?

Do you want to learn more about UCEDD, LEND and DDRC programs?

Would you enjoy meeting trainees, faculty and staff from AUCD member programs around the world?

Consider applying to be the AUCD 2006-2007 Virtual Trainee!

As part of AUCD's initiative to increase trainee involvement across the network and build future leaders, AUCD is seeking its next **Virtual Trainee** for the coming academic year!

This individual will work remotely from his or her home center/program for the coming academic year, working to continue to build and enhance a network among trainees at AUCD's UCEDD centers and LEND programs. The ideal candidate will be a trainee in the coming year, have previously acquired knowledge of their Center or Program and be interested in learning about the entire network of centers as well as national issues related to persons with disabilities and special health care needs. The person selected will work with AUCD national office staff, via electronic means, to build communications and information exchange among trainees throughout the network.

Duties of the Virtual Trainee include:

- Serve on the National Training Directors Council (NTDC)
- Generating ideas for increasing and supporting trainee involvement in the AUCD network
- Submit Provide regular updates of activities and issues on the AUCD website, listserves and newsletters

The Virtual Trainee will work closely with AUCD Central Office staff and be supported in attending the AUCD Annual Meeting & Conference and the Governmental Affairs Symposium, both in Washington, DC.

This is an exciting opportunity for a current trainee with experience to increase his/her knowledge of the national network and learn more about national level activities and initiatives. It is also an opportunity to exercise leadership on a national level within the AUCD network.

Interested candidates should forward a resume and brief letter of interest to
Crystal Pariseau (cpariseau@aucd.org) at AUCD. ■

Trainees:

Did you interact with a trainee from another program during your training? What did you think of the trainee listserve and message board?

Help AUCD and the National Training Directors Council improve these and other activities for next year's LEND and UCEDD trainees by completing a survey at www.aucd.org/aucd_trainees.



ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES
RESEARCH, EDUCATION, SERVICE

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LENDLinks

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

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

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2006 AUCD Annual Meeting and Conference: Forging New Partnerships for New Challenges Through Research, Education and Service

October 29-November 1, 2006
Renaissance Washington Hotel, Washington, DC

AUCD is pleased to announce the Call for Participation for the 2006 Annual Meeting and Conference. This year's meeting promises to be exceptionally exciting and informative as we explore our theme: ***Forging New Partnerships for New Challenges Through Research, Education and Service.***

With the theme of the conference focusing on partnership, attendees will have an opportunity to explore the AUCD network's collaborative efforts in leadership; new and exemplary partnerships at the international, national, state, and local levels; policymaking initiatives; supports and services to families and individuals; and training and technical assistance as instruments of addressing change.

We invite you to be a partner in this important event by submitting a proposal in response to the Call for Participation to become a part of our Conference agenda. This year's conference is broad and offers you the opportunity to showcase your research and achievements in diverse areas that highlight alliances with new and non-traditional partners. We welcome the submission of your important work in all areas.

All proposals must be submitted electronically. Information, guidelines and a link to the online proposal submission form can be accessed at www.aucd.org.

Deadline for submission of Proposals is June 1, 2006.

Visit www.aucd.org for a conference flyer to post at your site and to submit your electronic proposal application.

Check the website frequently for updates on workshops, speakers, and networking opportunities.