

**LEND LINKS**

## LEND Funding Announcements

The Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA) recently announced six funding announcements resulting from the Combating Autism Bill that was signed into Law this past December. The set of announcements are called the Combating Autism Act Initiative (CAAI) and constitute a significant source of additional funding appropriated by Congress to address a range of issues related to Autism Spectrum Disorders and related Developmental Disabilities. Many families, advocacy groups, and Autism and Disability Organizations worked extensively to make these financial resources available. The Requests for Proposals have a quick turnaround time period so that funds can be awarded in this fiscal year as proposal submissions are due at the end of June or very early in July. The individual announcements are:

- HRSA-08-144: *State Implementation Grants for Improving Services for Children and Youth with Autism Spectrum Disorder (ASD) and other Developmental Disabilities*
- HRSA-08-142: *Autism Intervention Research Network on Physical Health (AIR-P Network)*
- HRSA-08-143: *Autism Intervention Research Network on Behavioral Health (AIR-B Network)*
- HRSA-08-148: *Leadership Education in Neurodevelopmental and Other Related Disabilities (New LENDs)*
- HRSA-08-149: *Leadership Education in Neurodevelopmental and Other Related Disabilities (LEND Expansion - Supplemental Funding)*
- HRSA-08-147: *National Interdisciplinary Training Resource Center*
- HRSA-08-155: *State Public Health Coordinating Center for Autism*

Detailed information can be found at [www.grants.gov](http://www.grants.gov). Put Autism in the search field and all of the above announcements will appear.

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## AWARDS & HONORS

### Lea Ann Lowery (MO LEND) Named Outstanding Faculty

Kay Conklin, Missouri LEND

Lea Ann Lowery, clinical assistant professor of occupational therapy in the MU School of Health Professions (SHP), Occupational Therapy Faculty for the Tips for Kids program (Missouri's LEND) and adjunct faculty at the MU Thompson Center for Autism and Neurodevelopmental Disorders, has been named the Outstanding Faculty member for 2008 by the SHP Alumni Organization.



SHP alumni Organization President Ann Buerk, SHP Alumni Organization board member Nancy Fay, Lea Ann Lowery, winning outstanding faculty award in the school of health professions and Dean Rich Oliver

Lowery received the honor at the school's annual awards luncheon May 2.

In supporting Lowery's nomination for the award, TIPS Coordinator Kay Conklin said, "Lea Ann is a wonderful ambassador for the School of Health Professions."

Lowery has many accomplishments that led to her nomination and winning the award. In addition to starting a pediatrics occupational therapy clinic in the School of Health Professions, she redesigned the pediatrics portion of the SHP OT program to include a course in school based practice including the most current best practices and developed collaborative teaching endeavors with area schools, SHP's language preschool and the Thompson Center. Her OT students say they are impressed by her teaching skills, creativity, preparedness and organization.

Lowery holds a bachelor's degree in occupational therapy and a master's degree in education from the University of Missouri.

### Herbert J. Cohen (RFK, NY UCEDD/LEND) Appointed to CDC Board of Scientific Counselors

Dr. Herbert J. Cohen, Emeritus Director of the Rose F. Kennedy University Center on Developmental Disabilities and Emeritus Professor of Pediatrics and Rehabilitation at Albert Einstein College of Medicine, was recently appointed by Michael O. Leavitt, Secretary of Health and Human Services, to a three-year term on the new Board of Scientific Counselors, Coordinating Center for Health Promotion (CCHP), at the Centers for Disease Control and Prevention (CDC).

This board is established to ensure that the coordinating center has access to external viewpoints, the capacity to conduct peer review of scientific programs, and perform second level peer-review of research applications. The Board of Scientific Counselors, CCHP will advise the Secretary, HHS; and the Director, CDC; concerning strategies and goals for the programs and research within the national centers; shall conduct peer-review of scientific programs; and monitor the overall strategic direction and focus of the national centers.



## AWARDS & HONORS

### Oklahoma LEND Core Faculty Receive Accolades

Linda Wilson, PhD, OU LEND

Dr. Allen Knehans, Oklahoma LEND Core Faculty in Nutrition, accepted the position as the Chairman of the Department of Nutritional Sciences in the College of Allied Health at the University of Oklahoma Health Sciences Center (OUHSC), beginning July 1, 2008. Dr. Knehans brings a passionate support for the department and to the field of nutrition. As a David Ross Boyd Professor, Dr. Knehans is a consummate teacher and researcher, having received many research and education awards during his tenure at OUHSC.



Dr. Steve Wells, Oklahoma LEND Core Faculty in Social Work and Lea Ray, Long-Term Trainee in Social Work

Dr. Steve Wells, Oklahoma LEND Core Faculty in Social Work, was given one of six *Champions of Children Awards* from the Foster Care Association of Oklahoma at their breakfast held at the *Oklahoma Pathways to Adulthood Conference "Together We Can" 2008 Conference* where he was a presenter. Dr. Wells also wrote an article "Foster Parents and Parental Involvement In Schools: Examining an Important Role" that will be published in the back to school, July/August 2008 issue of *Fostering Families Today*.



Dr. Allen Knehans, Oklahoma LEND Core Faculty in Nutrition and Lisa Braden, Long-Term Trainee in Nutrition

### Westchester LEND Trainee Meghan Gleason Selected for Presidential Management Fellows Program

Karen Edwards, Westchester

Meghan Gleason, a member of the LEND class of 2008 at Westchester Institute for Human Development, and who will graduate on May 19 from the Columbia University School of Social Work with an MSW degree, has been selected for the *Presidential Management Fellows Program* and has accepted a two-year position in the program at the National Cancer Institute of the National Institutes of Health in Washington, DC. The purpose of the Program is "to attract to the Federal service outstanding men and women from a variety of academic disciplines and career paths who have a clear interest in, and commitment to, excellence in the leadership and management of public policies and programs." To learn more about this program, go to: <https://www.pmf.opm.gov/>.



LEND Trainees Meghan Gleason (left) and Victoria Stockton present their work at the New York State Dept. of Health

## NETWORK NEWS

### New LEND Consortium Conducts First Symposium

Guy Lotrecchiano, DC LEND, Children's National Medical Center

Donna L. Gilles, EdD, Virginia Commonwealth University

On Saturday April 5, 2008, approximately 40 trainees, faculty, and staff from the Mid-Atlantic LEND Consortium comprising Pennsylvania (Children's Hospital of Philadelphia), Maryland (Kennedy Krieger Institute), District of Columbia (Children's National Medical Center), and Virginia (Virginia Commonwealth University) met in Washington, DC, for a day of information-sharing regarding their respective LEND programs and planning for future collaboration with their consortium partners.

Planning for the event began last fall with participation of at least two faculty members and trainees from each of the four LEND programs. The logistics were easy decisions to make – the DC LEND graciously offered to host the symposium at their facility and to feed us, eliminating the budget issues of lodging and meals. Thank you, DC! As a result of discussion of the content and processes for the event, a needs assessment was developed and sent to several trainees and faculty for input into the agenda. The results indicated that trainees and faculty were interested in learning about best practices and the quality of services available in other states for families and people with disabilities. More specifically they requested information about the challenges facing other LEND programs, the current and potential research and leadership activities, and how other LENDs have developed their interdisciplinary clinic activities. The structure of the day consisted of large and small group discussions and presentations.

The morning agenda was comprised of presentations from the four LEND programs about their respective strengths in scholarship, training, and/or service. This format resulted in a wonderfully diverse exchange of information from faculty and trainees, not only describing their programs but discussing how coursework has informed practice, how practice has influenced leadership skills, and how leadership skills have affected their lives as professionals.

The afternoon was divided into three sessions where discussion points included a) what LEND activities are required, b) what are the expectations for these activities, and c) what barriers to meeting expectations have been encountered, and d) what goals, actions, and strategies should be in place for next year. The large group reconvened after the two breakout sessions and the facilitators presented the work of their respective groups. A good time was had by all, and the quality of the trainees' contributions was particularly impressive. Currently, we are finalizing the results of the breakout sessions which will generate a direction for future collaboration. We look forward to another symposium again next year.

### LEND Regional Retreat at The Ohio State University, Nisonger Center

Amy Hess, Nisonger Center

The Nisonger Center at The Ohio State University hosted the 2<sup>nd</sup> LEND Regional Retreat on April 9 – 10, 2008. Attending were faculty and staff from The UCLID Center at the University of Pittsburgh; Cincinnati Children's Division of Developmental and Behavioral Pediatrics LEND Program; the Center for Excellence in Disabilities (CED) at West Virginia University; the Nisonger Center LEND, and Crystal Pariseau from AUCD.

This two day event offered an evening reception to meet and exchange ideas with colleagues followed by a full day of presentations by each program highlighting unique program achievements. Crystal Pariseau presented an overview of AUCD and MCHB. Each presentation offered time for questions and discussion. The UCLID Center focused its presentation on outreach to culturally and linguistically diverse communities; West Virginia led an interactive session on building interdisciplinary teams and interdisciplinary training; Sheryl Feuer, Family Faculty member from Cincinnati Children's Division of Developmental and Behavioral Pediatrics, focused on Family Centered Training from a parent's perspective; and Nisonger LEND presented on their Service Learning training for leadership development. All of the presentations (and photographs) are catalogued on the Nisonger web site at <http://medicine.osu.edu/LEND/Retreat08/retreat08.htm>.

Feedback from attendees was positive and indicated the desire for continued LEND Regional Retreats next year. Dr. Dan Coury, Nisonger LEND Director hosted the day's activities and announced a "Name That Region" contest. Faculty and trainees from participating LEND are eligible to compete in a contest to develop a name for the region. The winner of the contest will receive "fabulous" prizes and bragging rights and will have their photo listed on the Nisonger and AUCD websites.



## NETWORK NEWS

### Day of the child Celebration, Cornelius, Oregon: "Equal Rights, Different Abilities"; "Diferentes habilidades, iguales derechos"

Claudia María Vargas, PhD, Roselyn Valerín, MD, Necia Davis, PT

The Day of the Child is a tradition in the Latino culture to celebrate and recognize publicly the value of children and the rights of children. Schools and families in Latin America organize events for children who get to enjoy the festivities and receive presents. For several years, the community of Cornelius, OR, has celebrated this event in April as a way to build community cohesion and intercultural understanding. Cornelius has a growing Latino community in what had been a predominantly white agricultural community. The festival quickly became a positive tradition bringing together the entire community.

Although the Day of the Child celebration has grown in reach and participation, families of children with disabilities have expressed concerns that the activities were not inclusive. They voiced these concerns through the "Cornelius Committee: A Vision for an Accessible Community/Comité de Cornelius: Una Visión para una Comunidad Accesible," an important outgrowth of a community engagement project conducted by the Oregon LEND faculty and trainees in the winter of 2006. The community expressed a desire to ensure accessibility to the activities for their children with special needs. Through the LEND community engagement connection, they sought an avenue to expand the Day of the Child celebration to all children.

LEND members became directly involved with this year's event. Our participation in the 2008 Day of the Child had the main goal of making the Day of the Child an inclusive event that would allow children with disabilities to truly participate. We found it important to work with families early in the planning process.



Photo credit: Ana Brouwer, Americorps Volunteer

The next stage was to for LEND members to join the community's Day of the Child Committee. Through the LEND's initiative, families of children with special needs were invited to join the organizing committee. Their participation was critical in allowing the committee, which had ample experience in planning and organizing the event but little or no experience in tailoring activities for accessibility, to understand the importance of inclusion and making the necessary accommodations to achieve inclusion.

In order to gather ideas, insight, supplies, and volunteerism from a larger group of people, LEND members worked to develop a collaborative relationship with graduate students at Pacific University and Portland State University and with an Americorps volunteer. The team of volunteers worked in concert with the organizing committee to plan and implement inclusive activities that helped to make the Day of the Child a success.

Seeing the children's faces and their expressions of happiness confirmed that they really were part of the activity and were glad to participate along with the families' joy at the fact that so much effort was made to include their children with disabilities. At the request of the mayor of Cornelius, the theme chosen for this year's event was "Equal Rights, Different Abilities/Diferentes habilidades, iguales derechos." Another important element was, upon the insistence of the families, to include pictures of children with disabilities in the celebration advertisements. And, of course, there were the necessary accommodations such as obtaining accessible portable restrooms and providing plywood paths to facilitate mobility for those in wheelchairs.

Working together, LEND members and mothers and children with disabilities were not only able to make the Day of the Child genuinely inclusive, allowing participation of children with special needs, but also establish a precedent for future activities. One of our main goals was to address various accessibility barriers, typical of a rural, agricultural, and resource-limited community, and make all the children's activities inclusive. However, the most important barrier that we helped overcome may have been the attitudinal barrier. Overcoming attitudinal barriers sometimes requires subtlety and at other times a more direct approach. At the outcome evaluation meeting of the organizing committee, all members had come to recognize that including everyone in the celebration really was important and that, in partnership with others, the tasks are doable.

We encourage future LEND trainees to participate and work closely with communities because it is, after all, in community settings where families and children with disabilities live, work, and play. It is also where they continue to encounter obstacles and barriers. This group of LEND trainees demonstrated true leadership which was critical in promoting and accomplishing accessibility for children with disabilities. This community-based experience was a valuable opportunity to share and use leadership and cultural responsiveness skills in order to promote the rights of the children with special needs. To see children with disabilities valued and included in this event, not to mention the obvious excitement on the part of the children themselves as they participated in the activities, made all the effort that went into the event so worthwhile. The collaborative community relationships that were built this year will serve as a foundation for continued partnerships in years to come. What a rewarding experience this turned out to be!

## NETWORK NEWS

### Leadership Education and Developmental Disabilities (LEADD) Program for Maternal and Child Health Professionals in the U.S. Virgin Islands

Karen Edwards, Westchester Institute for Human Development

The Westchester Institute for Human Development (WIHD), in association with the School of Public Health (SPH) at New York Medical College and in partnership with the Virgin Islands University Center for Excellence in Developmental Disabilities (VI UCEDD), is offering leadership education to maternal and child health professionals in the United States Virgin Islands (USVI). The name of this new program is Leadership Education and Developmental Disabilities (LEADD).

The program, supported by a Distance Learning Grant from the Maternal and Child Health Bureau, makes use of a blended learning methodology that relies on distance learning through computerized virtual classroom instruction, online discussion, and self-study combined with a small number of face-to-face sessions. Students participate in LEADD courses at the SPH via web conference twice a month and through in-person sessions in the USVI once per semester. Each trainee is advised by a faculty mentor from WIHD via teleconference and e-mail. Course curriculum focuses on topics in maternal and child health, with a strong focus on children with disabilities and their families. Topics include leadership development, health disparities and cultural competence, family-centered care, and the distinctive public health concerns of the Caribbean in general and the US Virgin Islands in particular.

The LEADD program at WIHD is directed by Karen Edwards, MD, MPH. John Laurence Miller, PhD, is the LEADD program coordinator and director of distance learning and continuing education at WIHD. His responsibilities include training WIHD faculty in distance teaching techniques and establishing and maintaining the distance learning partnership with the VI UCEDD.

Available to maternal and child health professionals on St. Croix, St. Thomas, and St. John, the program serves an urgent and unmet need for continuing education in the territory. Twelve participants have been accepted into the four semester, two year program. Upon completion, they will have earned a certificate and academic credits from the SPH. The current 10 students include pediatricians, nurses, a social worker, a physical therapist, and an educator. Many of them are employed by the health department in the Virgin Islands. One of the most important aspects of the collaboration is working closely with the territorial Department of Health to make the program responsive to the training needs of maternal and child health professionals in the USVI.

During each semester, students attend one to two hours per week of virtual classroom instruction online, and one extended weekend workshop per semester in the USVI. The first extended weekend workshop focused on communication skills for MCH professionals. Other classes are mainly taught by WIHD faculty via web conferencing. Mentoring is a very significant element in the instructional methodology. Access to mentors is essential to trainees in developing and carrying out an individualized leadership plan and an evidence-based longitudinal project.



MCH clinic:

Karen Edwards MD MPH, LEND Director and LEADD Director, WIHD; Ms. Patricia Penn, Director of MCH and CSHCN Program, DOH, St. Thomas, USVI; LEADD Trainee Arlene Smith-Lockridge, MD, Pediatric Public Health Physician, MCH & CSHCN Program, DOH, St. Thomas, USVI; LEADD Trainee Janney Hawley BSN, Head Nurse, MCH & CSHCN Program, St. Thomas, USVI



LEADD trainees, staff, and faculty at the Virgin Islands UCEDD during the March 2008 Extended Weekend Workshop on Communication Skills for MCH Professionals

# NETWORK NEWS

## 29th Annual Duncan Seminar Summary

John F. McLaughlin, MD, University of Washington LEND

The **29<sup>th</sup> Annual Duncan Seminar: Cerebral Palsy Today and Tomorrow: Updates in Evaluation and Treatment** was held on March 28, 2008 at Children's Hospital and Regional Medical Center, Seattle, Washington. The Duncan Seminar is an annual continuing education offering that focuses on the care of children and young adults with disabilities. Faculty in the Division of Genetics and Developmental Medicine, University of Washington, and the Outreach Education Program at CHRMC plan are responsible for organizing the Seminar. The Leadership Education in Neurodevelopmental Disabilities training program at the Center on Human Development and Disability, University of Washington, and the Office for Children With Special Health Care Needs, Department of Health, State of Washington, are key partners.

Over 200 health professionals representing ten disciplines attended. The participants heard the latest research regarding new treatment and therapy modalities. Issues around quality of life, activity, and transition to adult care were explored. The day began with a panel of families and young adults who gave personal insights into living with cerebral palsy. The keynote speaker was Diane Damiano, PhD, PT, Associate Research Professor, Department of Neurology, Washington University, Saint Louis. Dr. Damiano spoke on new approaches to physical therapy through activity and muscle strengthening. Topics included measuring physical activity, constraint induced therapy, transitioning to adult care, and medical/surgical management of hypertonia. The Seminar was seen via teleconference by health professionals in Yakima, WA, and by educators in the Mead School District, Spokane, Washington.

Each year, the Duncan Seminar Planning Committee presents the Duncan Award to an individual who has made significant contributions to families and children with special needs. The 2008 Duncan Award was presented to James E. May, MA, MEd, founding Program Director of the Washington State Father's Network and the national Father's Network.



## EVENT

### AAIDD and AUCD Webinar for Students and Young Professionals: Writing for Publication

Thursday, June 19, 2008. 3:00 - 4:00pm EST

The Committee on Student and Junior Member Recruitment and Retention of the American Association on Intellectual and Developmental Disabilities (AAIDD) and the Association of University Centers on Disabilities (AUCD) invite you to participate in an upcoming early career development webinar. AAIDD and AUCD are collaborating on a series of webinars aimed at meeting needs of students, trainees, and young professionals in the field of disabilities. The upcoming webinar will feature two well-respected scholars in the field: Susan Parish from the University of North Carolina-Chapel Hill and Charlie Lakin from the University of Minnesota. They will share their tips, advice, and wisdom regarding successful writing and publishing. Following their remarks will be an opportunity for Q&A.

Cost: FREE!

Registration can be found on [www.aucd.org](http://www.aucd.org) - click Trainees

You need: a phone line and a computer with internet.

## RESOURCES

### **Paper Highlights State and Local Innovation in Finance Policy for Child Behavioral Health Services**

Towards Better Behavioral Health for Children, Youth and Their Families: Financing That Supports Knowledge provides an overview of sources of funding (and their policy roots) that underwrite children's behavioral health services, illuminating the flaws and prospects of various policy choices. The working paper is the third in a series titled Unclaimed Children Revisited produced by the National Center for Children in Poverty. Although the paper focuses on public funding for mental health and on substance abuse services within the behavioral health arena, it also addresses related funding in education, child welfare, and juvenile justice. Topics include an overview of children's behavioral services, an overview of federal behavioral health funding streams and their impact, fiscal innovation in states and local communities, and challenges and opportunities. The authors conclude the paper with recommendations for policy actions to create and sustain a supportive federal and state fiscal environment. The paper is available at [http://www.nccp.org/publications/pdf/text\\_804.pdf](http://www.nccp.org/publications/pdf/text_804.pdf).

### **Preconception and Pregnancy MCH Knowledge Path**

The Maternal and Child Health Library released a new knowledge path edition, Preconception and Pregnancy. The knowledge path offers an electronic guide to current resources that analyze perinatal health statistics, describe effective prenatal care programs, and report on research aimed at improving access to and quality of prenatal care and improving perinatal health outcomes. Separate sections list consumer health resources and resources on specific aspects of preconception and pregnancy: childbirth, depression, drug and alcohol use, environmental concerns, fertility and infertility, nutrition, oral health, and tobacco use. View the path online at [http://www.mchlibrary.info/KnowledgePaths/kp\\_pregnancy.html](http://www.mchlibrary.info/KnowledgePaths/kp_pregnancy.html). Knowledge paths on other maternal and child health topics are available at <http://mchlibrary.info/KnowledgePaths/index.html>.

### **New MCH Teaching Tool**

Implementing the Medical Home Model in Minnesota: A Case Study is the first in a series of maternal and child health (MCH) case studies designed for classroom use by teachers of public health, MCH, health policy, evaluation, and health education in preparing students to serve as effective change agents working within the framework of Title V at national, state, and community levels. The study guide, prepared by a joint committee of the Association of Teachers of Maternal and Child Health and the Association of Maternal and Child Health Programs, presents one state's efforts to promote the medical home model of care for children with special health care needs. Selected topics include the importance of parents, the importance of physicians, the collaborative team, funding, and the future. Information on how to use the guide, including case study goals and objectives, key problems, discussion questions, role-playing opportunities, and assessing student progress, is provided. The study guide is available at <http://www.atmch.org/Projects.cfm>.

### **Manual Provides Guidance in Choosing Pediatric Developmental Screening Instruments**

Pediatric Developmental Screening: Understanding and Selecting Screening Instruments informs practitioners' selection and application of screening instruments in a range of practice settings. The Web-based manual, developed by the Commonwealth Fund, is based on a review of the scientific research on available developmental screening instruments.

Part 1 is designed to facilitate the selection of screening instruments by helping practitioners define their practice needs. Part 2 presents guides designed to facilitate practitioners' abilities to compare developmental screening instruments with respect to clinical utility in practice settings and validity, or sensitivity and specificity, in different populations and at various ages. An interactive Web feature (flow chart) is also available to answer questions about screening needs and make instrument recommendations. The manual is available at [http://www.commonwealthfund.org/publications/publications\\_show.htm?doc\\_id=614864](http://www.commonwealthfund.org/publications/publications_show.htm?doc_id=614864).



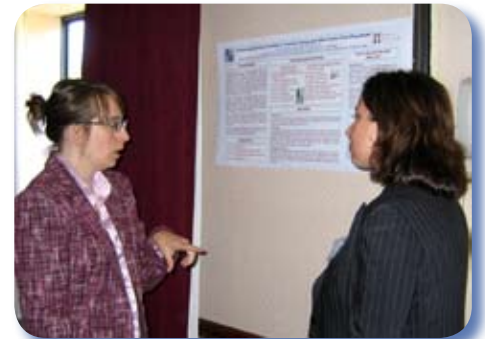
# TRAINEES

## Westchester LEND Trainees Meet with State Department of Health

Karen Edwards, Westchester LEND

On April 17, seventeen LEND trainees and five faculty members from the LEND Program at the Westchester Institute for Human Development traveled to Albany to meet with staff of the Division of Family Health of the New York State Department of Health. The meeting was hosted by Dr. Chris Kus, Pediatric Director of the Division of Family Health, who spoke about State Title V programs and state priorities for maternal and child health. Also in attendance were Susan Slade, RN, MS, CHES, Director of the Medical Home Unit, Ruth Walden, Family Specialist in the Division, and two representatives from the New York State Office of Child and Family Services. LEND Trainees presented the results of their Evidence-based team projects and took questions from the audience. The day ended with a wrap-up session about opportunities for collaboration between the Division of Family Health and the LEND Program, particularly around the team projects. The team presented the following projects.

- Evaluating the Effectiveness of Services Provided to Families During and After Foster Care Placement
- Technical Assistance Tools for Providers Working with Parents with Cognitive Disabilities
- Assessment of Consumer Awareness and Understanding of Newborn Screening
- Follow-Up of Young Children Diagnosed with ASD
- Follow-up of High-Risk Neonates
- School Age Assistive Technology Program



# TRAINEES

## My LEND Experience: Rebecca Roybal, NM LEND

I am a graduate student at the University of New Mexico completing my master's degree in Public Administration. Most people wonder what public administrators do, and I usually answer in a self-deprecating manner that we are paper-pushers. However, I like to think that we do much more than that because we play an important role in creating and managing programs with the end goal of helping as many people as possible.

I found that the majority of LEND trainees are from fields who will eventually work in a clinical setting with people with developmental disabilities. I admire and respect people who "work in the trenches" doing what I consider to be challenging and difficult work. During an introductory LEND seminar, we had to identify a profession that we felt we could never personally do. I chose medicine because where I am most comfortable is in front of a computer analyzing data. Fortunately, I have found that those attracted to the healthcare field tend to shy away from the administration side, and do not seem to delight at the thought of crunching numbers, grant-writing, or creating budgets. Needless to say, I consider myself lucky to have found my niche.

In my personal life, I have experience working with developmental disabilities. In December, 2006, my beautiful daughter was diagnosed with autism. I chose the LEND program because I wanted to learn how to become a leader in the public administration field in order to help other children like my daughter. My LEND experience has proved to be invaluable because I met trainees from a variety of disciplines, all of whom want to use their careers to help people with disabilities. I took the opportunity that

LEND afforded me to inform these future leaders what it is like to be a parent to a child with special needs, and to teach them what I know about autism. I also wanted to learn from them; I took note of their challenges and what I can do as an administrator to make their jobs easier and more rewarding so they will continue with their professional goals to help as many children as possible.

I recognize that there are many talented people who are passionate about working in the field of disability, but flaws in the system sometimes make it difficult for these talented people to do their jobs to the best of their ability. This knowledge can be frustrating, and in many ways the job of the public administrator can be thankless because resources will always be in short supply, yet the needs of children with special needs will continue to grow.

Through LEND I was able to see firsthand that despite challenges, there are wonderful people who are passionate about improving the lives of children with disabilities. One of my most memorable LEND experiences was my leadership

project, which included participating on two different committees to improve education for children with autism throughout New Mexico. At the special education subcommittee, I worked side-by-side with high ranking school administrators, professors from the University's College of Education, various autism specialists, and concerned parents. Our task was to create recommendations for the State Secretary of Public Education to improve education for children with autism. It was a formidable task, however, everyone involved was dedicated and hopeful that we could bring about positive changes. I recall one professor saying that what she wanted most was to give families hope. I was touched by this sentiment, both as a parent and as a public administration student, because I also want to create programs that will improve the lives of children with autism and their families.

My leadership project was a great opportunity for me to work with professionals to tackle a complex problem that is close to my heart. It was experiences like the leadership project that made LEND such a rewarding program for me. Everything I learned over the course of the year was outside the realm of traditional curriculum. The interdisciplinary experience, learning invaluable leadership skills, and the opportunity to work with community-level professionals was incalculable. These experiences continue to make me appreciate the dedication and perseverance of those who have chosen to work with people with developmental disabilities. Pursuing any career to work with people with disabilities requires specialized training and education, patience, understanding, and endless compassion. It is heartening to realize that so many people truly want to help in what can be a challenging field. As a parent to a special needs child, I want to do what I can to support these professionals, to thank them for what they do, and to encourage them to do all that they can to help others. In my professional life as an administrator I hope to keep the end-user in mind, so that I will remember that my job is to create quality programs that are efficient and produce positive results. When I am bogged down with spreadsheets and reports I will think of my daughter and all of the amazing and talented people that have helped her get to where she is today.

I know that my family's path will not be easy and there will be a lot of challenges along the way. Even though I expect to face many challenges both as an administrator and parent, I remain hopeful that everything I do in my career will help improve the lives of other children like my daughter. Likewise, I know that each LEND trainee will use their careers to bring about change, one step at a time. We each play an important part: whether we are a speech therapist teaching a child to speak, a social worker helping a family find resources, or a public administrator applying for the grant funding. While progress may not always be apparent, as long as we all keep moving forward, there is still hope for the future. My dream is that all of our combined efforts will lead to some big accomplishments someday.



# TRAINEES

## Oklahoma LEND Trainees Complete Team and Individual Leadership Projects

Mark Wolraich, MD, Director, and Linda Wilson, PhD, Training Director, Oklahoma LEND



The 2007-2008 Oklahoma LEND Long-Term Trainees developed and implemented a Team Leadership Project that incorporated aspects of teaming, leadership and research. The project was conducted in collaboration with the Sooner SUCCESS Program, a statewide systems change initiative focused on the MCHB Outcome Measures for children and youth with special health care

needs. A focus of the team project was to assist the Sooner SUCCESS staff in implementing a survey designed to: a) assess the satisfaction of individual families with the Sooner SUCCESS services that family received; and b) document the impact of those services as perceived by the family. The trainee team also developed a research hypothesis regarding the survey results and identified projected outcomes. The project allowed for experiences with stages of research design and implementation, shared leadership and various aspects of the teaming process including: reaching consensus; maintaining effective team communication; and utilizing the strengths of each member to function successfully as an interdisciplinary team. The project also provided an opportunity to collaborate with Sooner SUCCESS staff members who provided guidance and support for the trainees throughout the process. Oklahoma LEND Core Faculty provided ongoing feedback and mentoring with the project. Trainee disciplines represented were: Audiology, Developmental-Behavioral Pediatrics, Nursing, Nutrition, Occupational Therapy, Parent-Family Issues, Psychology, Public Health, Social Work and Speech-Language Pathology. The Team Leadership Project was presented by the trainee team to program faculty, colleagues and family members at the final Oklahoma LEND Leadership Reception on May 1, 2008.

An Individual Leadership Project also was designed and implemented by each trainee. Individual Leadership Projects included: 1) presentations related to family-centered care (Audiology: Jennifer Jackson), physician screening for Autism (Developmental-Behavioral Pediatrics: Kathleen Combs), and developmental disabilities/person-first language (Occupational Therapy: Lara Streight); 2) studies related to student attitudes toward a person with disabilities (Nursing: Sherry Gudgel), student and faculty attitudes and knowledge about individuals with disabilities (Psychology: Cynthia Muhamedagic), and impact of an educational intervention for parents prior to the premature birth of their infants (Public Health: Rob Wild); 3) a video of a parent's perspective about her young son with Autism; 4) an inclusive community-based gymnastics activity for young children (Nutrition: Lisa Braden); 5) a policy brief on access to health care as mediated by health insurance in the U.S. (Social Work: Lea Ray); and 6) creation of a family-friendly clinical environment (Speech-Language Pathology: Sarah Baker).

For more information about Oklahoma LEND, contact Dr. Linda Wilson at [linda-m-wilson@ouhsc.edu](mailto:linda-m-wilson@ouhsc.edu) or at (405) 271-5700 ext. 45176. For more information about the Sooner SUCCESS Program, contact Louis Worley, Sooner SUCCESS State Coordinator, at [louis-worley@ouhsc.edu](mailto:louis-worley@ouhsc.edu) or at (405) 271-5700 ext 45131.

# TRAINEES

## 2008 LEND Fellow Convocation

David Helm, PhD, ICI LEND

The Institute for Community Inclusion LEND program held their convocation May 16, 2008. The event celebrated the year's activities of the fellows and each presented a summary of their major project for the year. Most of the fellows emphasized their work in community-based organizations (CBO) having collaborated with CBO's serving Somali, Latin American, African-American, Chinese, Vietnamese, Asian-Pacific, and Haitian populations in the greater Boston area. One fellow reported on a psycho-educational parent group that she participated in while two others summarized their research projects.

Drs. Allen Crocker and David Helm served as masters of ceremony and Dr. Janice Ware was the convocation speaker relaying some of her recent work on autism spectrum disorder and genetics. Family members, hospital and LEND faculty, CBO executives and friends of the program joined in the occasion offering congratulations and best wishes to the LEND fellows.



Institute for Community Inclusion - Children's Hospital Boston

Front: Lourdes Mary Daniel, Carol Vasconcellos, Carrie Pekar Jasper, Abigail Ross, Joanne Venus-Williams.  
Back: Sunday Taylor, Robin Strickman, Jessica Mercer Young, Bonnie Thompson, Megan Snyder, Laurey Brown, Michele Carol, Jay Berry. Absent: Cedric Ireland

## UCLID Fellow Looks More Closely at the Prescribing Practices of Pediatric Oncologists

Laly Fernandez, UCLID Center LEND

Based on warnings placed on all antidepressant bottles and a study done at the Children's Hospital of Philadelphia, UCLID LEND interns decided to examine the prescribing practices of pediatric oncologists across eight hospitals nationwide. Although it seems feasible that children receiving treatment for cancer experience more depression, especially during more intensive phases of care, numerous studies examining this issue found a very low prevalence of depression in this population group when compared to the general population (DeJong and Fombonne 2007). Currently, there is not sufficient research available on the use of antidepressants in children who have cancer.

A survey was specifically developed for this research project and was composed of 17 questions. The questionnaire targeted the use of specific antidepressants called selective serotonin reuptake inhibitors (SSRI) and other mixed-mechanism medications used to treat depressive and/or anxiety disorders. The survey was distributed to over 100 pediatric oncologists across the nation including MD Anderson Cancer Center and St. Jude Children's Research Hospital, as well as our own Children's Hospital of Pittsburgh.

We hope this study will further examine the prescribing practices of pediatric oncologists and pediatric oncology fellows who see children with cancer who may have depressive or anxiety disorders. In addition, we sought to determine why medications are initiated and how the FDA black box warning is monitored. Finally, we will examine the role of psychology and psychiatry when treating children with cancer who have depression or anxiety. We hypothesized that a majority of pediatric oncologists prescribe SSRI's for a minority of their patients. The remainder of this work is exploratory as no previous studies have examined these issues but we hope the outcome will make treatment of this special population more efficient and evidence based.

## TRAINEES

### UNC Chapel Hill- Center for Development and Learning Trainee Research

Julia Tarr, UNC



Julie Hammer, Ph.D., a psychology trainee from the UNC-CH School Psychology program, successfully defended her dissertation entitled "Attention and Behavioral Inhibition in Young Males with Fragile X Syndrome and/or Attention-Deficit/Hyperactivity Disorder" on January 28, 2008. Last year, she completed a practicum at the Center for Development and Learning and she is currently completing a year-long internship.

Findings from Dr. Hammer's dissertation research suggested that, when compared to boys diagnosed with AD/HD and mental-age matched typically developing boys, those with fragile X syndrome (FXS) demonstrated significant deficits with inhibitory control on both the adapted visual and auditory continuous performance tests (CPTs) and on an experimental Day/Night task that measures inhibition. Boys with FXS had inconsistent deficits of sustained attention on the CPTs and on the standardized measure of sustained attention. Additionally, it was found that the boys with FXS had a significantly slower mean response time to targets on the visual CPT. There were no family or child variables (e.g., chronological age, maternal education) that predicted performance on the measures of sustained attention or inhibition. Future research is needed to further explore executive function deficits in boys with FXS. Congratulations, Dr. Hammer! [www.cdl.unc.edu](http://www.cdl.unc.edu)

### AUCD 2008: November 8-12, 2008 in Washington, DC

This year is a combination of tradition, change, and forward movement; thus the theme of paving the way and building pathways. Whether you have been creating a new path, expanding an existing road, or creating a super-highway by taking interventions to full-scale, we invite you to participate in this year's Annual Meeting by sharing your expertise. We hope that you will submit your proposal for a presentation and help us pave the way!

AUCD Conference sessions include concurrent sessions (60-90 minute learning sessions), a poster session (with over 70 posters presented), and a media room (showing movies and videos created for and by the network). Submit your presentation for consideration today!

- Call for Participation due: June 20, 2008
- Notifications of acceptance: by August 22, 2008

A limited number of **Trainee Travel Stipends** will once again be offered – watch the website for details!

AUCD invites you to submit an application to participate in our AUCD 2008 Annual Meeting. See the AUCD website for the materials you will need as you prepare to submit your application.





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RESEARCH, EDUCATION, SERVICE

## LENDLinks

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### Submissions

Items of interest to LEND programs may be submitted for consideration to [cpariseau@aucd.org](mailto:cpariseau@aucd.org). High quality electronic images are encouraged.

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