



ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES  
RESEARCH, EDUCATION, SERVICE

# LEND LINKS

## AUCD Annual Meeting & Conference 2007

**TOMORROW IS HERE TODAY: THE INTERRELATIONSHIP OF  
RESEARCH, EDUCATION, SERVICE, & POLICY**

**November 10-14, 2007**

**Washington, DC**

The 2007 AUCD Annual Meeting and Conference is a special opportunity to share your interests, talents, and perspectives with the AUCD network and its partners. The theme is broad and emphasizes the interrelationship of research, education, service, and policy at the international, national, state, and local levels. This year's annual meeting is a call to act, understand, expand, and integrate findings and education with policy and practice which will lead to inquiry, understanding, and learning that will reinforce the expansion of a system which embraces self-determination, interdependence, and inclusion.

Join your colleagues as we challenge how we think about today in order to use it to shape how we think about tomorrow.

Visit [www.aucd.org](http://www.aucd.org) for more information and to submit your proposal before June 22nd!

### IN THIS ISSUE

AUCD Annual Meeting...	1
Network News...	2
Resources...	11
Trainee Corner...	12

## NETWORK NEWS

### Interactive Workshop on CSHCN Broadcast Across 9 Training Sites

Lee Wallace, Nutritionist, Boling Center for Developmental Disabilities LEND

A distance learning workshop in March, "Interdisciplinary Leadership Training in Overweight Prevention and Intervention for Children with Special Health Care Needs," was hosted by the Boling Center for Developmental Disabilities (BCDD) at the University of Tennessee Health Science Center in Memphis, TN. Funded by a grant from the Maternal and Child Health Bureau, there were a total of 109 attendees across nine sites during the two-day workshop. Workshop participants came from a variety of professions, including nutrition, nursing, pediatrics, social work, occupational therapy, physical therapy, and psychology.

Four of the sites have worked together in the past on remote interactive televideo transmissions:

- Boling Center for Developmental Disabilities LEND at the University of Tennessee Health Science Center in Memphis, TN (host)
- Strong Center for Developmental Disabilities LEND at the University of Rochester in Rochester, NY
- Child Development and Rehabilitation LEND in Portland, Oregon
- University of Tennessee at Knoxville.



This year, during the announcement and advertising of this Workshop, additional organizations in the Southeast Region expressed interest in participating and BCDD welcomed the collaboration of the Atlantic Coast Consortium of training programs in a trial of internet-based interactive transmission of the conference. Five members of the Atlantic Coast Consortium participated:

- Center for Development and Learning LEND at NC Chapel Hill
- Partnership for People with Disabilities LEND at Virginia Commonwealth University
- Mid-Tennessee Interdisciplinary Instruction in Neurodevelopmental Disorders LEND, Vanderbilt Children's Hospital, Center for Child Development
- Mailman Center for Child Development LEND at the University of Miami, Miller School of Medicine, Department of Pediatrics
- University of South Carolina Center for Disability Resources (UCEDD)

The ability to ask questions of the speakers and have some discussion across all nine sites while participating from a site close to home was rated highly by participants. For people unable to attend the Workshop, the program is now developed into an online, self-paced course available through BCDD at [www.utmeh.edu/bcdd/training/community/cshcn.htm](http://www.utmeh.edu/bcdd/training/community/cshcn.htm).

### Controversial "Ashley X Treatment" Provides Rich Forum for Discussion of Ethical Issues and Team Decision-Making During Collaborative LEND Teleconference

Susan Taylor-Brown, Elizabeth Baltus Hebert, and Stephen Sulkes, Strong Center for Developmental Disabilities

The Rochester LEND Program hosted a teleconference examining the ethical and clinical challenges of a complex case with the University of Vermont and University of New Hampshire LEND Programs. The public became aware of this case in October 2006 when Gunther and Diekema published "Attenuating growth in children with profound developmental disability: a new approach to an old dilemma" in the Archives of Pediatrics & Adolescent Medicine. This appears to be the first time that attenuated growth for individuals with developmental disabilities has been described in the literature. An editorial written by Brosco and Feudtner took issue with the surgical and pharmacological approaches to the care dilemmas identified by Ashley's parents and called for a stronger societal response to care challenges while recognizing the many complexities imposed by the case. In January 2007, Ashley's parents started a blog advocating the use of the "Ashley Treatment" for other individuals with developmental disabilities as appropriate. The exposure of this controversial treatment stimulated an international response with over three million responses reported on Google to date, along with several additional commentaries in subsequent issues of the same journal.

As practitioners, we frequently experience tension in balancing the needs of the child, the parents and the disability rights community. The internet is altering the nature of this tension by making this information widely and rapidly available and open to public discourse internationally. As care for people with developmental disabilities is increasingly in the public spotlight, international advocacy efforts have taken a new direction, as evidenced by this case. As practitioners, we need to be well informed regarding these multifaceted concerns and to work toward treatments that ensure the rights of individuals with disabilities are protected. The increasingly open communication and access to information should benefit patients, families, and providers alike.

Through this teleconference, we sought to develop a collaborative team approach that could join these groups to improve the care of children who have extensive care needs that are inadequately addressed by our society. This is an excellent teaching case for all programs preparing professionals to work with children with developmental disabilities and their families.

*"Ashley X Teleconference" continued on page 7*

## NETWORK NEWS

### AUCD Signs On to "Friends of Title V" Appropriations Request Letter

The following letter was recently sent to both the House and Senate Appropriations Subcommittees requesting an FY2008 appropriations amount of \$750 million for the Title V MCH Block Grant. AUCD continues to participate in regular meetings with Friends of Title V. This group works together in support of the Title V MCH Block Grant. Many thanks go to AMCHP staff Josh Brown and Susan Campbell for organizing and hosting these meetings.

May 17, 2007

*The Honorable David Obey, Chairman, Subcommittee on Labor, Health and Human Services, Education and Related Agencies; Committee on Appropriations, U.S. House of Representatives, Washington, D.C. 20515*

*The Honorable James T. Walsh, Ranking Member, Subcommittee on Labor, Health and Human Services, Education and Related Agencies; Committee on Appropriations, U.S. House of Representatives, Washington, D.C. 20515*

Dear Chairman Obey and Ranking Member Walsh:

*We, the undersigned organizations, are writing to request an appropriation of \$750 million for Title V Maternal and Child Health (MCH) Block Grant in FY 2008, enabling states to provide vital health care services to millions of pregnant women, infants and children, including those with special health care needs.*

*The MCH Block Grant provides a wide range of health services and fosters the prevention of disease and disabling conditions for over 33 million women and children across the country. State health agencies use MCH Block Grant funding to provide women with prenatal and postnatal care, screen newborns for genetic and hereditary conditions, support childhood immunizations, reduce infant mortality and prevent childhood accidents and injuries. Block grant dollars also allow states to develop critical infrastructure, including the training of health professionals, developing comprehensive models for community services, and the testing and evaluation of innovative practices. In addition, MCH programs work in coordination with state Medicaid agencies, the Special Supplemental Nutrition Program for Woman, Infants and Children (WIC) and other programs serving this population. This collaboration ensures that every dollar is used to provide necessary services without duplication.*

*In FY 2007, \$693 million was appropriated for the MCH Block Grant, \$31 million below the FY 2004 appropriation. Since 2000, the number of women and children served by the MCH Block Grant has increased by over 5 million; however funding has decreased over the same period. Currently, MCH Block Grant funds have enabled states to reach more than 80 percent of infants, 50 percent of pregnant women and 20 percent of children in this country. Without additional funding, state Maternal and Child Health Bureaus will not be able to continue to meet the increasing demand for services.*

*We strongly urge you to fund the MCH Block Grant to \$750 million. With these funds, states can resume serving women and children, ensuring that all mothers and their children will have access to high quality health services. Thank you for your time and consideration. For further information, please contact, Joshua Brown or Susan Campbell with the Association of Maternal and Child Health Programs at (202) 775-0436.*

Sincerely,

Ambulatory Pediatric Association  
 American Academy of Pediatric Dentistry  
 American Academy of Pediatrics (AAP)  
 American Pediatric Society  
 Association of Maternal and Child Health Programs (AMCHP)  
 Association of Medical School Pediatric Department Chairs  
 Association of Schools of Public Health (ASPH)  
 Association of State and Territorial Health Officers (ASTHO)  
 Association of Teachers of Maternal and Child Health (ATMatCH)  
 Association of University Centers on Disabilities (AUCD)  
 CityMatch  
 Division for Early Childhood of CEC  
 Epilepsy Foundation

Family Voices  
 First Focus  
 Healthy Start  
 IDEA Infant Toddler Coordinators Association (ITCA)  
 March of Dimes Foundation  
 National Assembly on School-Based Health Care  
 National Association of County and City Health Officials (NACCHO)  
 National WIC Association  
 Society for Adolescent Medicine  
 Society for Pediatric Research  
 The Arc of the United States  
 United Cerebral Palsy

## NETWORK NEWS

### Iowa-Hawaii Pediatric Dentistry Project

Suzanne Pearson, Training Director, Center for Disabilities and Development, Iowa

One of several comprehensive leadership projects to be undertaken by our trainees this year was developed by Elaine Himadi, MD, Pediatric Fellow in Developmental and Behavioral Pediatrics. Before joining the LEND program, Dr. Himadi lived and worked on Hawaii's Big Island, and while there learned that water on this island was not fluoridated, and that the incidence of tooth decay was one of the highest in the nation. Dr. Himadi was also aware that the only Medicaid provider for dental care had closed its doors, leaving children who were uninsured or who carried Medicaid insurance without dental services. Early in the training year, Dr. Himadi had the opportunity to interact with four dental residents from the MCHB Pediatric Dentistry program at the University of Iowa and also taught a course in Physical Diagnosis for these same residents. Her prior knowledge of dental issues for children in Hawaii and her interaction with the Pediatric Dental residents resulted in the development of a project to help meet the dental needs of these children.

With support and encouragement from Dr. Michael Kanellis, Iowa LEND Director for Pediatric Dentistry, and Dr. Richard M. Burke, Jr., DMD, Director of Pediatric Dentistry, Center for Disabilities and Development, Dr. Himadi contacted former colleagues in Hawaii as well as Catholic Charities, and Dr. Louise Iwaishi, Hawaii LEND Director. Their collaborative efforts resulted in the development of a project to provide free dental evaluations and services to children in need on Hawaii's Big Island. Four Iowa dental residents have obtained a community practice license and a temporary Hawaii dental license and will work with their supervisor, Dr. Richard Burke, utilizing a Mobile Dental Van to provide free dental evaluations and services to 100-200 children between the ages of 1-10 years.

This service was provided during the week of May 14-18, 2007. Data was collected on the number, age, and gender of children served, and whether these children have Medicaid or are uninsured. Data was also collected on the number and type of dental issues, treatment plan and treatment rendered. The goal of this project is to raise awareness of this issue among the dental community, meet the dental needs of as many children as possible, and to encourage other dentists to volunteer their time and expertise, so that the dental needs of these children can continue to be addressed.



Dr. Elaine Himadi, MD

### Dental Outreach at the Utah Regional LEND Program

Brett Packham, DDS & Clark Romney, DDS

While in the Utah Regional LEND program, our eyes opened to the constant and ongoing care that the children with disabilities need. Through lectures and other activities, we observed the overwhelming burdens these families can face. The URLEND program helped us understand the important role each medical and other professional disciplines play in these children's lives.

We feel that dentistry is one of the most important aspects of health care. Studies show that people with healthy mouths, few caries, and no gingival disease tend to also have better overall health. As part of our dental training at Primary Children's Medical Center in Salt Lake City, Utah, we are trained to work with children and young adults with disabilities. We feel that oral hygiene is often times overlooked or put on the backburner because of the other pressing medical treatments taking place. In the future we hope that dentists will play a more active role in the overall health of children with developmental disabilities.

We desire to become more involved in the community and help underserved children, including those with special health care needs, have healthier smiles. Through the ABLE clinic we were able to identify a need for dental assistance at two community sites, the Jordan Valley School and a United Way program called Sealants for Smiles.

Jordan Valley School is the center-based school located in Midvale, Utah. Jordan Valley serves 239 children with severe disabilities ages 5 to 22. The goal for our project at Jordan Valley was to work with the children, parents, and staff of the school in increasing the children's overall dental health. We spent one day a quarter at the school doing various activities with the faculty and children. We arranged limited exams, fluoride varnish treatments, sealants as needed, and referrals for children to local dentists.

As part of our project we educate parents on how a child's nutrition affects their dental health, the process of tooth decay, and how tooth decay can better be prevented. Prevention is our top priority with these children. We also work with the parents and faculty on proper brushing techniques and ways to make dental hygiene easier. We try to impress on parents that tooth decay can lead to major infections that can compromise their child's health.

The United Way Sealants for Smiles initiative provides preventative dental care and oral health education for all first graders attending Title 1 schools in Salt Lake City. We hope future residents will continue to help the United Way make a difference in the lives of children who do not have access to dental care. We have dedicated one full day a month to Sealants for Smiles, where two dentists will provide screenings, education, referral sources, and minor treatment as needed. This program does not focus on just children with special needs but rather prevention for an underserved population.

Creating a worthwhile community program has been a great learning experience for both of us. We learned to work with people such as principals, teachers, and parents from local schools in coordinating efforts. Through LEND, we have become much more comfortable with the interdisciplinary approach to solving problems as we met with groups and participated in discussions with trainees from other disciplines. Part of being a leader is being willing to leave your comfort zone, and we have done much more of this since we began the LEND program.

## NETWORK NEWS

### ICI Boston LEND Convocation

David Helm, PhD, Training Director, ICI Boston

May 11, 2007, was the ICI - Children's Hospital Boston LEND convocation celebrating the successful completion of the year's activities. The 10- long-term fellows each presented on their experience with a community based organization (CBO). Each is required to work with a CBO to learn about the culture of the population served by the agency as well as to develop a small project to benefit the organization. This year's fellows worked with the Great Wall Center, Latin American Health Institute, Vietnamese-American Civic Association, Inc., Haitian American Public Health Initiative, Somali Development Center, Massachusetts Asian and Pacific Islanders for Health, Roxbury Multi-Service Center, Massachusetts Immigrant and Refugee Advocacy Coalition and Urban PRIDE. The convocation speaker this year was Dr. Rooshey Hasnain, an ICI LEND faculty who spearheads the coordination with our community partners. Dr. Hasnain addressed Passionate Leadership-Transformational Leaders and encouraged the graduates to become leaders, to make a difference. Mr. Abdirahman Yusuf, the Co-founder and Executive Director of the Somali Development Center gave the final words of the day and commented on hope, change and community.



ICI Boston 2007 LEND graduates  
Front Row: Gaby Harrison, Alexis Dugan, Tara Tatelman Hedvat, Rebecca Bunn, Rachel Kerls  
Top Row: Matthew Rouillard, Patricia Kennedy, Ashley Speliotis, Molly Greaney, Rhea Taveres

### UAB Civitan-Sparks Clinics: 40 Years of Community Service

Jim Willett, Media & Web Resources, University of Alabama at Birmingham

The University of Alabama at Birmingham (UAB) Civitan-Sparks Clinics celebrated its 40th anniversary on March 19, 2007, with an all-day event that included consumers, past and present trainees, and clinical staff. The UAB Civitan-Sparks Clinics, originally known as the UAB Chauncey Sparks Center for Developmental and Learning Disorders, was established in 1967 as Alabama's federally funded university-affiliated program (UAP).

Through the years the clinics have provided clinical and community services for thousands of individuals and families seeking evaluation and intervention for a broad range of physical, developmental, learning, and/or behavioral challenges, including cerebral palsy, autism, ADHD, inherited metabolic diseases such as phenylketonuria (PKU), Down Syndrome, and Rett Syndrome. In coordination with its MCH LEND mission to train tomorrow's leaders in neurodevelopmental disabilities, the Civitan-Sparks Clinics has shared its expertise throughout the US and the world.

The event, held in conjunction with the annual Simpson-Ramsey Lectureship, included a presentation of new research by keynote speaker Darryl De Vivo, M.D., Professor of Neurology and Pediatrics and Director Emeritus of the Pediatric Neurology Service at Columbia Presbyterian Medical Center in New York City, as well as other presenters discussing topics related to the lectureship theme "Newborn Screening," and a panel discussion featuring consumers and health professionals.

Historical perspectives on the accomplishments of Civitan-Sparks Clinics were provided by former Sparks Center Director John Benton, M.D., and Harriet Cloud, UAB Professor Emeritus, a nationally recognized Pediatric Nutritionist.

The event also served to recognize community partners who participate in the Civitan-Sparks Clinics newborn screening activities. Awards were given to outstanding community programs at the Alabama Department of Public Health - Bureau of Clinical Laboratories and Bureau of Family Health Services. In past years an award was also given to an outstanding former trainee of the Sparks Clinics, but this year, Dr. Alan Percy, Director of the Civitan-Sparks Clinics felt it was time to honor and recognize the many former trainees who have been working hard as faculty and staff at the Civitan-Sparks Clinics. Among those recognized were: Brittany Allison, Kirstin Bailey, Fred Biasini, Belinda Blackstone, Catherine Burke, Amy Cooper, Beth Darwin, Karen Echols, Chris Eidson, Allie Green, Elizabeth Griffith, Kristi Guest, Gina Harris, Bart Hodgens, Janice Jackson, Snehal Khatri, Nicole Kuzmicic, Dan Marullo, Kameron Partridge, Alicia Roberts, John Thornton, Julie Woodruff, and Larry Zachow.

The event was well attended by many consumers, faculty and trainees who were also the first to see a DVD slide presentation of images made through the years at the clinics by the Civitan-Sparks Instructional Technology staff. The Civitan-Sparks Clinics are an integral of the UAB Civitan International Research Center and provide a crucial link between consumers, the national and local developmental disabilities network, researchers in the basic sciences, and trainees in programs related to the neurosciences and neuro-developmental disorders.

For images from the event please visit our web site: [http://circ-uab.infomedia.com/news.asp?record\\_no=9494](http://circ-uab.infomedia.com/news.asp?record_no=9494).



Darryl De Vivo, MD discusses Glut-1 deficiency syndrome



## NETWORK NEWS

### Munroe-Meyer Institute Poster Session

Kellie Ellerbusch, Munroe-Meyer Institute, Nebraska

Nebraska LEND trainees concluded the research component of their training program with the Eighth Annual Munroe-Meyer Institute Poster Session on April 25<sup>th</sup> on the campus of the University of Nebraska Medical Center. Trainees, working in teams or individually, presented the findings from research projects they developed and implemented throughout the 2006-2007 academic year. LEND students presenting were: Michelle Swanger-Gané, Katie Woods, Katrina Kersch, Jaime Mukherjee, Terri Mathews, Jenny Kronberg-Haire, Meg Floress, Angela Gibson, Valerie Gortmaker, and Christy Johnson.



UNMC Poster Session

Six LEND research projects were presented. Topics included virtual reality training to improve coordination, head-pointing and eye-pointing technology, perceptions of pediatric behavioral consultation, and education for parents of children newly diagnosed with autism spectrum disorders. MMI faculty members judged these presentations for clarity and appropriate rationale, methodology, organization, results, and conclusions. Cash prizes for the best overall presentations were awarded to LEND Trainees Meg Flores and Angela Gibson for their research regarding "The Effectiveness of Teacher-Child Interaction Therapy on Behaviorally At-Risk Preschool Children" and also to LEND Trainees Valerie Gortmaker and Christy Johnson for their presentation of "Focus on the Family: An Interdisciplinary Approach to Addressing Childhood Obesity". Eleven other posters were presented by other long-term MMI trainees and faculty, including research projects in Physical Therapy, Psychology, Nursing, and Human Genetics.

LEND Trainees gain experience in presenting research findings by participating in the poster session, as well as an oral presentation of their research project in which they are questioned and evaluated by fellow LEND students and faculty. "The trainee research projects are an integral component of our LEND program," said Dr. Cindy Ellis, LEND Director. "Presenting these projects to the UNMC community gives exposure to the LEND program and is a wonderful opportunity to showcase the excellent work of our LEND trainees."

### Virginia LEND Synergy Genetics Grant Releases On-line Learning Module

Meghan Strenk, LEND Genetic Counseling Trainee, VA



In 2005, the LEND program at Virginia Commonwealth University received funding from the Association of University Centers on Disabilities (AUCD) for the Synergy grant. The purpose of this grant is to increase the genetics component of LEND training, increase the leadership training of genetic counseling students, and increase diversity in the healthcare field. In aiming to increase the genetics component of their training, one of Synergy's goals is the development of three computer based learning modules on the topics of genetic awareness, family history, and newborn screening. The first module, on genetics awareness, is almost complete, and is currently undergoing final revision. It includes interactive case studies in which participants can make decisions and receive feedback, as well as explore resources about a variety of topics related to genetics and disability.

Recently the module was distributed to the LEND network, and evaluated for its effectiveness in increasing genetic awareness in LEND faculty, graduates, and trainees by Meghan Strenk, second-year genetic counseling student and VaLEND trainee. Analysis of the 42 surveys returned showed a statistically significant difference between the pretest responses and the posttest responses.

This indicates the module is successful in increasing genetic awareness. It is our hope that these modules will be useful in LEND training, as well as for identifying resources that may be helpful in discussing or learning about genetics and genetic conditions. The genetic awareness module is available, and subsequent modules will become available over the next year, on the Internet at <http://www.medschool.vcu.edu/ofid/id/genetics/>. Please feel free to check it out. Comments or questions may be addressed to Dr. Joann Bodurtha at [bodurtha@vcu.edu](mailto:bodurtha@vcu.edu) or Lauren Vanner Nicely at [lvannernicely@mcvh-vcu.edu](mailto:lvannernicely@mcvh-vcu.edu).

## NETWORK NEWS

### Kansas Seating Clinic Via Interactive Televideo Conferencing

Norbert Belz, MHSA

For more than 20 years the Developmental Disability Center (DDC) at KUMC has helped children with neuromuscular diseases find the best wheelchair options. The DDC's interdisciplinary seating clinic recently partnered with Kansas University's Center for Telemedicine and Telehealth (KUCTT) to help more Kansas' families receive this needed specialty service. The same team approach is used via videoconferencing between KUMC and distant sites. Seating clinic provides an interdisciplinary team approach to prescribing wheelchairs that allows children a mobility (manual or power) system for accessing their environment. A typical core interdisciplinary team consists of the family, a physician who specializes in rehabilitation, a nurse, PT, OT, Social Work, and unique to this clinic, the Certified Rehab Technology Supplier (CRTS). The CRTS, or rehabilitation supplier, is involved from the beginning of the evaluation through the actual fitting of the wheelchair. Telemedicine utilizes interactive televideo conferencing (ITV) to provide health services to patients who normally are unable to access care, particularly in rural areas. Simply put, the patient sees the treatment team through live video conferencing. For the telemedicine wheelchair seating clinic, the DDC team collaborates with the patient and their family, a rural PT, and the rehabilitation supplier through ITV. The seating clinic over ITV has already helped several children in rural Kansas. Two students were in dire need of a consultation and unable to make the 700 mile, 10-hour trip due to students' health and family restrictions. Because of the innovation, both patients were given recommendations that addressed their physical need, allowing adjustments and repairs to be made in one case (saving many dollars to Medicaid), and a prescription for a new wheelchair in the other. The clinic also offers a unique opportunity for LEND trainees to learn about the needs of rural families and the role of technology to meet these needs.

#### Ashley X Teleconference

*continued from page 2*

**Background of Ashley X Case:** Ashley, a six-year old child with and experiencing precocious puberty, was brought to the pediatric endocrine clinic for treatment. Her parents requested interventions to stunt her future growth in order to improve her quality of life in the family, increase the likelihood of her remaining at home with her family, and reduce the potential for sexual abuse by caretakers. The treatment consisted of invasive and irreversible surgical and pharmacological treatment of Ashley including a hysterectomy, breast bud removal, and appendectomy, followed by high dose administration of estrogen.

**Teleconference Objectives and Format:** As a result of participating in the teleconference, LEND trainees were able to:

- Discuss pros and cons of Ashley's treatment
- Apply ethical principles to Ashley X's case
- Compare & contrast a medical construction of Ashley's condition and treatment with a social constructionist view as articulated by the disability rights community
- Articulate ways to approach conflict management within a team, and
- Describe advocacy roles.

A variety of modalities were incorporated into the two-hour conference to bring the case to life. After a mock team treatment discussion, the 3 LEND programs worked independently to identify the pros and cons to the "Ashley X Treatment." Then, a role play of a team member inappropriately imposing his views on the parents was employed. Members of the University of Rochester's Ethics Committee participated in the ensuing discussion.

**Summary:** This case is an excellent teaching case for all of us providing care to children with developmental disabilities and their families. It illustrates the interplay of parents' needs, challenges in caring for children whose care is physically demanding and time consuming, working through complex team dynamics in challenging cases, and working with disability rights advocates.

Good team functioning requires open and clear communication. Team members have a responsibility to address concerns appropriately within the team. At the same time, as team members we have to work together in resolving areas of disagreement regarding patient care and not put the patient and family in the middle of team dissention.

Complex cases like this challenge us to find solutions to help the situation. The answers are not clear-cut and we need to work together to improve the medical and social services available to children like Ashley while ensuring that her rights are protected. It is the team's responsibility to provide unbiased information to the family to empower them to make informed decisions regarding the care of their child. However, the question remains: Who has the right and the responsibility to make the final decision on unclear, ethically questionable issues such as this case illustrates?

**Postscript:** The majority of discourse has focused on the ethical dimensions of this case. Recently, a new development regarding the legality of the "Ashley Treatment" was reported. The Washington State Protection and Advocacy System found that Ashley's civil rights had been violated because a court order for the hysterectomy had not been obtained. The Washington Protection and Advocacy System entered into a remediation agreement with Children's Hospital. For more information on the contents of this article, please contact: [Susan\\_Taylorbrown@urmc.rochester.edu](mailto:Susan_Taylorbrown@urmc.rochester.edu).

## NETWORK NEWS

### Promoting "Leadership Through Legislative Advocacy": A New Oklahoma LEND Trainee Activity

Linda Wilson, Training Director, Oklahoma LEND & Louis Worley, Sooner SUCCESS State Coordinator

Oklahoma LEND and Sooner SUCCESS, a statewide interagency systems change initiative, are collaborating on a series of Issue Briefs to provide targeted information about community-based strategies that promote family-centered, culturally effective, interdisciplinary, and comprehensive service approaches. Issue Briefs provide background information and activities focusing on the principles of Oklahoma LEND and the overarching goals of Sooner SUCCESS. The Oklahoma LEND-Sooner SUCCESS collaboration allows the interdisciplinary training of health care and related professionals to include experience with a statewide community-based systems change initiative.

Expanding on this collaboration and to enhance trainee participation in community-based improvement activities, this year's 2006-2007 Oklahoma LEND long-term trainees were each asked to develop an article that: 1) addressed one or more of the MCHB Outcome Measures for children and youth with special health care needs and Oklahoma LEND Principles; 2) had relevance for a broad interdisciplinary audience; and 3) was written in the Issue Brief format. The submitted articles were reviewed by the Issue Brief Co-Editors, Linda Wilson, Oklahoma LEND Training Director, and Louis Worley, Sooner SUCCESS State Coordinator. One article was selected to be disseminated as the Summer 2007 Oklahoma LEND-Sooner SUCCESS Issue Brief. Ms. Amanda Cash, Long-Term Trainee in Public Health, submitted the selected article titled "Leadership through Legislative Advocacy". The selection announcement was made by Dr. Mark Wolraich, Oklahoma LEND Program Director, at the program leadership presentations and reception held on May 3, 2007. Ms. Cash is completing her Doctorate in Public Health at the University of Oklahoma Health Sciences Center and has been selected as a Health Resources Services Administration (HRSA) Fellow in the Office of Women's Health. There she will assist in supporting the agency's commitment to women's health across the lifespan, and participate in projects that support the mission of the Maternal and Child Health Bureau and the nine Departmental strategic goals related to ensuring access to quality care and reducing the burden of disease throughout the nation.

The Issue Brief written by Ms. Cash will be disseminated to family members, self advocates, service providers, organizations and agencies focused on services and supports for individuals with special needs and their families, community representatives, and others at the local, state, and national levels. If you are interested in receiving the Issue Brief, contact Jeannene Leffler with the Sooner SUCCESS Program at [jeannene-leffler@ouhsc.edu](mailto:jeannene-leffler@ouhsc.edu) or (405) 271-6824 ext. 45101. Please indicate if you prefer to receive the Issue Brief electronically or by mail.



Amanda Cash, Mark Wolraich, Louis Worley, Linda Wilson

### Kennedy Krieger Institute Activities

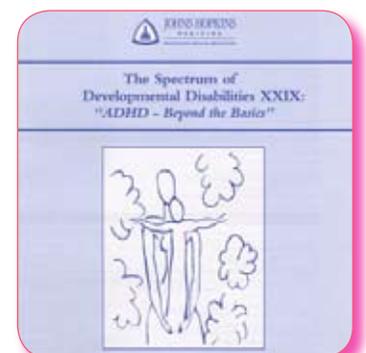
Bettea Hoofnagle, MLS, MS, Director, Training Administration

The 29th annual Spectrum of Developmental Disabilities Course was held March 26-28 at the Johns Hopkins University School of Medicine. The conference topic this year was Attention Deficit Hyperactivity Disorder, and approximately 300 professionals attended the 2 ½ day interdisciplinary continuing education course. Areas of focus included: Implications for Service Delivery, Neurobiology, Diagnostic Margins, Classroom Effects, and Treatment and Outcome. Faculty from throughout the country attended the conference including the LEND projects at Oregon Health and Science University, Virginia Commonwealth University, University of North Carolina, University of Oklahoma Health Sciences Center, and the University of Tennessee Health Science Center, as well as the Johns Hopkins/Kennedy Krieger Institute Joint Center for Developmental Disabilities.

The KKI Department of Neuropsychology held its first annual Neuropsychology Research Forum, featuring presentations of ongoing and recently completed research by Institute faculty, staff and trainees. In collaboration with the Department of Developmental Cognitive Neurology, the first Neuropsychology Research Forum featured a paper session with presentations on:

- recovery following traumatic brain injury,
- fMRI investigation of motor inhibition in ADHD, and
- development and validation of new measures of strategic planning for use with children with neurodevelopmental disorders.

Following the paper session, there was a poster session featuring neuropsychological research involving children with autism, reading disorders, ADHD, alcohol-related neurodevelopmental disabilities as well as typically developing youth.



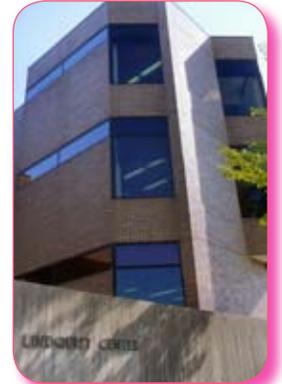
## NETWORK NEWS

### R\*E\*A\*C\*H at the University of Iowa

Dennis C. Harper, PhD, Iowa LEND Director

R\*E\*A\*C\*H (Realizing Educational and Career Hopes) is a postsecondary collegiate program for students with multiple learning disabilities at the college of education, the University of Iowa.

There is growing body of literature that suggests that adults with multiple learning disabilities (MLD) and their families are far more likely to be productive participants of their communities when educational opportunities are provided to them. Postsecondary education has become an increasingly important prerequisite to independent adult living. Completion of postsecondary education significantly improves an individual's chances of securing meaningful employment, a hallmark of a successful adult life. With this in mind, the University of Iowa is developing a comprehensive postsecondary educational program as part of the University's commitment to educating Iowans. The REACH program at Iowa is positioned to respond to these needed collegiate practices and opportunities. The University of Iowa REACH Program is a two year, postsecondary certificate program based in the College of Education located on the campus of The University of Iowa. The program focuses on meeting transitional needs of students with MLD in an inclusive university setting. The program focuses on educating the whole person and emphasizing life skills for independent living in the community at large. Education emphasizes academic skill building, career preparation, life skills, socialization, and career placement following graduation. The program relies upon evidence-based practices, state-of-the-art curriculum development, and includes instruction in classrooms, in residence halls, and at job sites. Learning is small group focused and coupled with coaching in real work settings. The curriculum focuses on courses offered by the "REACH faculty" of the College of Education and selected University of Iowa courses from departments and colleges and faculty across campus. Support services are in place to promote student success in all educational and career settings. Students live in a residence hall on The University of Iowa campus, and receive support from specially trained residence assistants who are currently part of the College of Education graduate education programs. A fully inclusive collegiate environment provides students with age appropriate community opportunities and interactions with other university students. The faculty and staff of the program are assisted by graduate and undergraduate students from The University of Iowa programs in the College of Education as part of their own educational programs. The REACH Program of The University of Iowa anticipates admitting its first class of students in the fall of 2008. Dr. Dennis C. Harper, current LEND Director at the Center for Disabilities and Development at the University of Iowa is the Director of REACH. [www.education.uiowa.edu/reach](http://www.education.uiowa.edu/reach).



College of Education-Lindquist



University of Iowa

### News from the Hawaii LEND

Jean Johnson, Hawaii LEND

As announced on May 14, Hawaii was one of 13 states receiving a "Money Follows the Person" grant. University of Hawaii-Center for Disability Studies (UH-CDS) worked with the state Medicaid agency to draft the application. The grant was based on a successful demonstration project conducted by UH-CDS over the past three years. This grant will bring more than \$10,000,000 to the state over the next five years to provide alternatives to nursing home care. UH-CDS will be conducting the evaluation component of the grant.

UH-CDS' Peter Dowrick was informed of the funding of an OSEP grant entitled "Multimedia for Literacy in English Language Learners with Disabilities." This is a two-year Steppingstones Project. It will implement a series of studies to measure the efficacy of the extensively piloted "TeenACE Reading and Writing" program.

## NETWORK NEWS

### Vermont Family Fellow Lisa Bushey

Julianne Nickerson, Family Faculty Director, Parent to Parent of Vermont



Vermont's Interdisciplinary Leadership and Education of Health Professionals (VT-ILEHP) LEND program is pleased to announce our Family Fellow, Lisa Bushey. Lisa has participated in the LEND program in the role of family faculty for the Family Centered Care Parent to Parent match. This element of our program matches the trainees and fellows with families for a 40-hour intensive family experience which includes trainees spending time with families outside of the disciplines in which they are working by creating partnerships, understanding the family perspective, and working on a family project. Lisa has taken the step out of the family teacher role to that of trainee. She is participating in the ILEHP program over two years in order to allow for the needs of her family to be met as well as the requirements of the program. Completion of her first year has been very rewarding and challenging. Changing her lens from Lisa's family to other families has been a wonderful process. The leadership opportunities and growth for Lisa this past year have been tremendous. We at the VT ILEHP are thrilled to have the opportunity to expand the family role in our program. As the Family Support Faculty member it is exciting to provide families additional ways nurture their already present leadership skills.

### Angelman Syndrome Foundation Grant to UNH LEND

Stephen Calculator, UNH LEND

Stephen N. Calculator, a LEND faculty member and Professor in the Department of Communication Sciences and Disorders at UNH-Durham is continuing work on a grant funded by the Angelman Syndrome Foundation. The grant, "Communication/educational programs for students with Angelman Syndrome in inclusive classrooms: A look at best practices" began with an extensive review of the literature on evidence-based practices related to inclusive education, especially those pertaining to the provision of related services such as augmentative and alternative communication. Next steps will involve surveying parents' priorities for their children, approximately 25 in all from across the USA, and determining current practices in the schools. The project will conclude by sharing information with teams to assist them in planning more effective inclusionary programs for the next school year.

*AUCD will soon be accepting applications for the 2007-2008 Virtual Trainee (VT)*

*Being the AUCD VT is a great opportunity to put your leadership skills into practice on a national level. In addition, the VT is supported to attend national meetings of the AUCD network and encouraged to think creatively in forming relationships among AUCD trainees across the country. To learn more about the Virtual Trainee opportunity and to apply, visit the [Trainee section of the AUCD website](#).*

## RESOURCES

### New in Disability Statistics

The Cornell StatsRRTC is pleased to announce the release of several new products related to disability statistics:

1. Transcripts, Power Point slides and audio files from our State-of-the-Science Conference are available at <http://www.ilr.cornell.edu/edi/p-srrtc-2006conference.cfm> . This was a two-day conference held last October, entitled "The Future of Disability Statistics: What we Know and Need to Know."
2. For those interested in *surveying people* with disabilities, you may be interested in reading "Surveying Persons with Disabilities: A Source Guide (Version 1)," by Jason Markesich, James Cashion and Martha Bleeker of Mathematica Policy Research, Inc. The *Source Guide* is a structure annotated bibliography of studies that address survey methods and disability. It is available at <http://digitalcommons.ilr.cornell.edu/edicollect/1222/>.
3. We have also added a comprehensive set of statistics to our web site, [www.DisabilityStatistics.org](http://www.DisabilityStatistics.org). These statistics take advantage of the massive sample size of the 2005 American Community Survey. We provide prevalence and employment statistics by state, race, Hispanicity, education level, age groups, gender, and disability type.

For more information about disability statistics and StatsRRTC products and publications, please feel free to email us at [DisabilityStatistics@cornell.edu](mailto:DisabilityStatistics@cornell.edu) or call us at (607) 255-1540.

### CDC Study: Most women of childbearing age in the United States do not get enough folic acid

According to a recent CDC study most women of childbearing age in the United States are not getting enough folic acid. CDC researchers analyzed nutrient intake data reported by non-pregnant women aged 15–49 years who participated in the National Health and Nutritional Examination Survey, 2001–2002. In the study, more Hispanic and black women reported low folic acid consumption than white women.

- Only eight percent of non-pregnant women reported consuming at least 400 micrograms of folic acid from fortified foods
- In the study, the proportion of Hispanic (6.8%) and black women (5.0%) consuming the recommended level of folic acid from fortified foods alone was lower than the proportion of white women (8.9%)
- Fewer Hispanic (21%) and black (19.1%) women than white women (40.5%) consumed at least than 400 micrograms of folic acid from supplements and fortified foods

Consumption of 400 micrograms of folic acid daily has been shown to significantly reduce serious birth defects such as spina bifida or anencephaly. At the present level of folic acid fortification, most women need to take a folic acid– containing dietary supplement to achieve the recommendation of 400 micrograms per day.

The entire article, "Race-ethnicity Differences in Folic Acid Intake in Women of Childbearing Age in the United States After Folic Acid Fortification: Findings from the National Health and Nutrition Examination Survey, 2001–2002" published in the May issue of the American Journal of Clinical Nutrition, is available at <http://www.ajcn.org/cgi/content/abstract/85/5/1409>.

For more information on folic acid, please visit [www.cdc.gov/folicacid](http://www.cdc.gov/folicacid).

### Champions for Progress is now Champions for Inclusive Communities (ChampionsInC)

You may know this group by its former name, Champions for Progress the National State Leadership Center for CYSHCN. Last spring, they began a new center called Champions for Inclusive Communities (ChampionsInC), also funded through MCHB-DSCSHN. Its focus has shifted from state leadership development to achieving Performance Measure 5, which states "Services are organized so families of CYSHCN can use them easily and are satisfied with the services they receive." View resources and subscribe to the biweekly newsletter at <http://www.championsinc.org/>

## TRAINEE CORNER

### Parent Leaders

Victoire Jacques, LEND Family Trainee, WIHD



My name is Victoire Jacques and I am a LEND fellow at the Westchester Institute for Human Development. The purpose of this piece is to encourage all parents and especially family specialists for their dedications and courage toward their children regardless of their needs.

I have been thinking about the different challenges that Family Specialists and we parents face daily and still keep on performing miracles in the live of our children. We parents, who are facing the challenge of raising children with special healthcare needs, are overachievers.

First, for those of us who are not in the health care field, throughout the years of caring for and nurturing our children, we have learned to become their doctors and nurses without the formal education or licenses. For example, we nurse and care for our children when they are sick and require our immediate attention. This task may be hard at the beginning; however, we learn to become experts and soon assume the role of doctors and nurses when our children need our help.

Moreover, when our children are sick and at home, we analyze signs, symptoms, and emergency and non-emergency situations. Thus, we are able to report our concerns to our health care providers. That way, our children are able to receive the best care and services.

Second, as parents, we have become counselors for those who are unable to advocate for themselves. As family specialists, we have become advisers and advocates for those with special needs. We make sure that the voice of every family with children with special health care needs is heard throughout the states. We advise leaders how to improve services to the community and health care professionals how to reach out to other parents and provide the essential services to families who are unable to access our health care system for their children. Thus, services are available and accessible to parents for their children. Most of all, we are resourceful because through experience, we learn to navigate the system and rise up to become future leaders.

Finally, parents and family specialists are dedicated and willing to go the extra mile to change the system of care for children with special health care needs. Isn't it something that we, parents and family specialists, should celebrate and be proud of? Indeed, we are overachievers.

### News from the 2006-2007 AUCD Virtual Trainee

Rene Jamison, Kansas LEND

#### 2007 Trainee Call for Papers posted on the AUCD website

Trainees have submitted summaries of their research or trainee projects, which have been posted to the Trainee section of the AUCD website. As Virtual Trainee, I have enjoyed reading these projects and encourage everyone to take a moment to read through these incredible entries. It is apparent that AUCD training programs have a talented group of leaders who have contributed to making a difference in their communities and will continue their leadership in the future. Thank you to everyone who has taken the time to share their work. It's not too late to get involved and share your research by completing this "Call for Papers". I will continue to take entries throughout the summer. Guidelines are provided on the website: <http://www.aucd.org/template/page.cfm?id=496>

As this training year draws to a close, I want to thank all my fellow trainees who have contributed to and participated in AUCD activities. I appreciated trainees communicating through the listserv and providing comments and photographs following the Disability Policy Seminar for the website. It was nice to see so many trainees make connections this year at both the AUCD Annual Meeting and the Disability Policy Seminar. I particularly enjoyed the trainee receptions, dinners, encouraging networking, and late night chats about our future as leaders in this network! I would also like to thank AUCD for this opportunity to serve as this year's virtual trainee. This position has allowed me continued leadership development, increased knowledge about disability and policy, and considerable opportunities for networking-what an incredible experience! I look forward to my continued involvement as a postdoctoral fellow and in my future career. Special thanks goes to Crystal Pariseau for encouraging me, highlighting opportunities, and providing support to complete my activities.

Good luck to everyone who is graduating or beginning new opportunities over the summer. Although your traineeship may be coming to an official end in your program, you are always welcome to stay involved with the AUCD network. You may continue to receive messages on the listserv if you continue your membership and you will want to stay active in checking the website for career opportunities, funding resources, policy issues, and AUCD program news. Good luck and best wishes in becoming leaders in this field!





ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES

RESEARCH, EDUCATION, SERVICE

## LENDLinks

### Editor

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

### Submissions

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

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

Current and back issues of LEND Links can be found on the AUCD website.

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## Trainee Papers Posted on [www.aucd.org](http://www.aucd.org)

AUCD trainees are called to share their research projects, leadership projects, or other program projects produced during their traineeship. This is an opportunity for you to share your hard work with others, network with AUCD programs and faculty, participate in scholarly activities, and generate discussion and ideas for future projects. Upon review and edits, summaries are posted on the AUCD website in the Trainees section. Interested trainees should send papers to AUCD Virtual Trainee Rene Jamison. By sending in papers, trainees give AUCD permission to post their submission on this website for an undetermined amount of time.

Papers will be accepted throughout the summer and posted as they are submitted. We are looking forward to reading many papers! Submitted papers and submission guidelines are posted on the website.

### Trainee Papers 2007

- Supporting Children with Parents Have Cognitive Challenges: Needs Assessment Results from Specialized Clinics in Utah, *Catherine Haarstad, URLEND*
- Infants/Toddlers Assessment Tool (ITAT), *Dorit Radnai-Griffin, Delaware UCEDD*
- The LEAD Project (Leadership, Employment, Advocacy, Development) for Youth and Emerging Leaders with Developmental Disabilities, *Erin Bastien, Delaware UCEDD*
- Transition of Young Adults in Special Education to Post High School Life, *Julie Pelletier & George Wootton, URLEND*
- New Directions Early Head Start Program Wide Self Assessment, *Lauren Francis, Delaware UCEDD*
- The Effects of Parent-Child Interaction Therapy (PCIT) on Problem Behaviors in Three Children with Autistic Disorder, *Rene Jamison, KUMC*