

# LEND LINKS

## Upcoming LEND Events

### Disability Policy Seminar 2008

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**ADVANCING DISABILITY POLICY IN AN ELECTION YEAR**

**March 2-4, Washington, DC**

Join us for a pragmatic view on the unique challenges and opportunities facing the Congress and White House as the 2008 political campaign proceeds. A special AUCD Trainee Reception is planned for Sunday evening.

Visit [www.aucd.org](http://www.aucd.org) for registration, hotel information, factsheets, and more!

### MCHB Training Branch All-Grantees Meeting (and LEND Directors Spring 2008 Meeting)

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**65 YEARS AND COUNTING:**

**THE LEGACY AND FUTURE OF MCH LEADERSHIP**

**April 22-23, 2007, Washington, DC**

Grantees of the training branch should save the date for this important meeting.

The Spring 2008 LEND Directors Meeting will be held April 23-24 following the MCH event. Due to the busy schedule of events, there will not be a LEND Discipline Meeting this year.

Visit [www.aucd.org](http://www.aucd.org) for registration and more information.

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## IN THIS ISSUE

## AWARDS

### Dr. Dennis Stevens Receives Award



The South Dakota Perinatal Association honored Dr. Dennis Stevens' dedication to children and families with the 2007 Pioneer Award. The Pioneer Award recognizes the efforts of those who break ground in caring for new families and educate others about the South Dakota Perinatal Association's mission. More than 300 healthcare professionals belong to the South Dakota Perinatal Association. Association members cited Dr. Stevens's excellence as an educator, mentor and researcher. Dr. Stevens's current research focuses on the developmental impact of light and sound in neonatal intensive care units (NICU). Dr. Stevens joined Sanford Children's Hospital and Specialty Clinic (formerly Sioux Valley) in 1980. He is a professor of pediatrics at Sanford School of Medicine at The University of South Dakota. He is Director of the SD LEND program.

**CONGRATULATIONS DR. STEVENS!**

### Contompasis Receives Partners in Care Award

Jennifer Nachbur, University of Vermont

University of Vermont (UVM) Associate Professor of Pediatrics Stephen Contompasis, MD, received a Partners in Care Award from Parent to Parent of Vermont and the Vermont Parent Information Center at the 2007 Partners in Care Conference at the Sheraton Burlington on December 6, 2007.

The Partners in Care Award was established in 1995 to honor those who exemplify and promote the ideals of family-centered care. Family-centered care redefines the roles of families, health care professionals, educators, and communities in providing for individuals with special needs. It places the family and the individual at the core of care provision, and promotes an atmosphere of respect, support, collaboration and, empowerment.

Contompasis, a developmental pediatrician and director of the Vermont Interdisciplinary Leadership Education for Health Providers program, a LEND, at UVM, was recognized for his commitment to both practicing and teaching family-centered care, as well as for his understanding that change in medical and public policy systems is required to fully realize family-centered ideals.

One of the individuals who nominated Contompasis for the award stated "[Dr. Contompasis] is very unique as a physician -- and a gift to the disability community -- in that he constantly strives for and invests tremendous personal energy in envisioning and championing systematic changes to improve outcomes for children and families."



A total of six Partners in Care Awards in four categories were presented at the meeting.

**CONGRATULATIONS DR. CONTOMPASIS!**

# AWARDS

## 2007 Capute Award Recipient: Allen C. Crocker, MD, FAAP

This article was written and originally published by the American Academy of Pediatrics: Then National Center of Medical Home Initiatives for Children with Special Needs: <http://www.medicalhomeinfo.org/about/CSOCWD2007Capute.html>

Dr. Frederick Palmer's remarks on Dr. Crocker receiving the Arnold J. Capute Award:

Dr. Crocker is one of the fathers of interdisciplinary care for children with developmental disabilities. Allen is a graduate of MIT and then Harvard Medical School. He completed his pediatric residency at Children's Hospital of Boston and has remained there for his entire career with appointments to the faculty of both the Harvard Medical School and School of Public Health. Allen is widely known for his leadership of the Developmental Evaluation Clinic at Children's which he has directed since 1967. But his interest in developmental disabilities extends much further back. Dr. Judy Palfrey in her nomination letter states that "at Children's Hospital, Dr. Crocker's name is practically synonymous with Down Syndrome since he has cared for children with this disorder over 50 years." He is, she states, "much beloved by families from throughout New England for his commitment and loving care for the children whose citizenship he has fought to protect and whose opportunities he has labored to ensure throughout his life."

Dr. Crocker's Developmental Evaluation Clinic remains the heart of one of the initial MCHB-sponsored LEND programs, and a national model. In that setting Dr. Crocker and his colleagues have trained countless professionals across many disciplines. These graduates are among the leaders in our field. Dr. Crocker's contributions in advocacy are astounding. His approach is gentle but unwaveringly persistent; scholarly but always accessible; rigorous but approachable. I have seen this in his contributions to the development of the network of LEND programs and what is now the Association of University Centers on Disabilities which he served as president in the 1980s. But he has provided similar leadership to dozens of non-profit entities, state agencies, professional organizations and university task forces. Of note to this audience, he served the Massachusetts Chapter of the Academy as Chair of the Committee on the Child with Disabilities for 11 years and as President of the Society for Behavioral and Developmental Pediatrics.

Dr. Crocker has been a tireless advocate for the prevention of disability and particularly its secondary and tertiary effects on function. (He would be especially interested in today's session on measurement of function.) He worked in the late 1980s and early 1990s to develop a comprehensive schema of indicators for evaluating the effects of prevention efforts in childhood disability.\* He called the items the "Fateful 43" because of their close relationship with critical child outcomes. This list of sentinel indicators is worth reviewing today.

Dr. Crocker's co-edited texts, *Developmental-Behavioral Pediatrics and Medical Care for Children and Adults with Developmental Disabilities* are on the shelves of many of us here today. I want to read a few sentences from Allen's overview chapter in the latter volume:

"To be involved with a developmental disability is a life-long adventure. There are personal implications and service components in each of life's stages. We have not yet found the way to naturalize the process, but grace and redemption can be felt during many moments along the trip. It is particularly rewarding when this is achieved for the aging population by those who love them."

On behalf of the Council it is a personal pleasure to present Dr. Crocker with the 2007 Arnold J. Capute Award.



\*Crocker AC. Data collection for the evaluation of mental retardation prevention activities: The fateful forty-three, *Mental Retardation*, 30:303-317, 1992.

## CONGRATULATIONS DR. CROCKER!

# NETWORK NEWS

## Greetings from the MCH Training Program!

Madhavi Reddy, MCHB

We hope that you are having a successful and productive New Year in your LEND programs. As you may know, the MCH Training Program will be hosting a Training All Grantee Meeting on April 22-23, 2008 at the Omni Shoreham Hotel in Washington, DC. The meeting is designed to provide an opportunity for all currently supported MCH Training Programs to share innovations about leadership training activities, address issues of mutual interest regarding the MCH Training Program, and strengthen networks. Goals of the meeting include sharing grantees' promising practices and problem solving strategies, providing new adult education and leadership development tools and strategies, supporting development of mechanisms for on-going information sharing, problem solving, and innovation among MCH Training Program grantees, and celebrating the outcomes and achievements of the MCH Training Program. No more than two representatives from each currently supported MCH Training grant are invited to attend the All Grantee Meeting. Meeting registration information will be available in the upcoming weeks. If you have questions about logistics, please direct them to Sheryl Mathis at (202) 828-5100 or sheryl.mathis@altatum.org.

Training Program staff members are working with other MCHB staff members to develop a plan for implementing the portions of the Combating Autism Act that came to HRSA. You will hear more from us shortly regarding funding opportunities.

Thank you to the LEND workgroups that are examining the current MCH training performance measures. Your feedback will inform the process as we re-submit performance measures for Office of Management and Budget (OMB) approval later this year.

We look forward to seeing you at the All Grantee Meeting in April!

## Tammie Picklesimer: 2008 AUCD Policy Fellow

Please join AUCD in welcoming our new Disability Policy Fellow, Tammie Picklesimer, who joined the national office on January 10. Tammie is a doctoral student in the field of exceptionalities at the University of Hawaii and a trainee at the Center on Disability Studies where she conducted research on postsecondary education for students with disabilities among other projects. She is also most recently a high school teacher in an alternative learning program for at-risk students. At AUCD, Tammie will be assisting the legislative affairs staff in pursuing its legislative goals, especially in the area of education policy, as well as assisting program staff to fulfill ADD contract activities. Tammie can be contacted at [tpicklesimer@aucd.org](mailto:tpicklesimer@aucd.org).



## 2008 Pierre Decouflé Fellowship

A New AUCD-NCBDDD Post-Doctoral Fellowship

AUCD is honored and pleased to announce a new AUCD-NCBDDD Fellowship program - The 2008 Pierre Decouflé Fellowship. Named after the late Dr. Pierre Decouflé, this Fellowship will be awarded to an individual seeking a career in the health research field who will benefit from an applied epidemiologic and developmental disabilities research learning experience with NCBDDD at CDC.

AUCD is seeking a faculty, staff, current trainee, or recent graduate (within the last two years) candidate from the UCEDD, LEND, and/or DDRC network who is passionate about advancing research in the area of developmental disabilities. The fellow will devote his/her effort with the Developmental Disability Branch within NCBDDD by working on the ongoing Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) data base, and on special projects with data from the MADDSP as well as other data sets containing information on potential risk factors for developmental disabilities. This fellowship is located at NCBDDD Headquarters in Atlanta, GA.

Applicants should have a doctoral degree in a public health, allied health, or education field. The fellow is expected to have a good knowledge of basic epidemiologic principles and methods and experience in data analysis. Familiarity with using personal computers is required. Microsoft Access, SPSS, and/or SAS programming and data analysis is desirable but not required. Minimum desired coursework includes basic statistics and research methods. Good writing skills are also desired. The salary range is \$60,000 - \$70,000 range based on education and experience, and the start date is negotiable.

To obtain additional information, please view this announcement on the AUCD website or contact Sue Lin (301-588-8252 ext. 212).





## NETWORK NEWS

### WV LEND Goes to Camp

Camp Gizmo, an assistive technology camp for children birth to eight with disabilities and their families, has been held each year since 1994 at the West Virginia Schools for the Deaf and Blind in West Virginia's Eastern Panhandle. As a collaborator in organizing the camp, the Center for Excellence in Disabilities at West Virginia University assists with operating Camp Gizmo and provides a variety of training opportunities for LEND mentors, trainees, and other WVU students in health and related professions. For many years, LEND mentors in speech pathology, social work, nutrition, behavioral psychology, and occupational therapy have offered evaluations and training to children and their parents.

Camp Gizmo staff identifies "focus children" from around the state who are supported at Camp by a team of professionals, caregivers, and families to identify assistive technology needs and strategies for in home implementation. Parents, professionals, and caregivers attend workshops during the day while children attend Kid's Camp, where assistive technology strategies are tried in an inclusive environment with non-disabled peers. Inclusive evening activities involve all Camp Gizmo attendees and include swimming, an ice-cream social, and karaoke night.

LEND trainees have the opportunity to observe, participate on teams, attend workshops, work in Kid's Camp, and assist with evaluations in their disciplines. LEND mentors provide evaluations and help teams with integrating discipline-specific goals into planning for use in children's home communities.



### Nisonger Center Coordinates Williams Syndrome Conference

In September 2007, Dr. Marilee Martens, a Nisonger Center psychologist, coordinated the first Great Lakes Regional Conference on Williams Syndrome. The conference consisted of both a medical and a regional conference for professionals, trainees, and families with children with Williams Syndrome. Several LEND trainees attended the Medical Conference where internationally recognized authorities on Williams Syndrome (Dr. Elizabeth Dykens, Dr. Paige Kaplan, Dr. Carolyn Mervis, and Dr. Colleen Morris) presented on their research and clinical experience. Trainees also participated in the Regional Conference where parents and families met with the Williams Syndrome panel consisting of several of the presenters from the Medical Conference as well as LEND faculty and other disability experts. While parents and family members met with professionals, children with Williams Syndrome, siblings, and other trainees enjoyed themselves at a water park. Over 200 people attended the Conference which received extremely positive evaluations.



In response to an increased demand for integrated clinical services for children with Williams Syndrome, a Multidisciplinary Williams Syndrome Clinic has been created. The Williams Syndrome Clinic is a collaboration between Nisonger Center and Nationwide Children's Hospital and includes a Developmental Behavioral Pediatrician, Behavioral Psychologist, Educational Psychologist, Speech/Language Pathologist, Occupational Therapist, and Physical Therapist. Consultation with Genetics, Cardiology, and Audiology is available as needed. This clinic meets twice a month and provides a valuable teaching experience for LEND Trainees.

For further information, please contact Dr. Marilee Martens at (614) 688-3112  
Marilee.Martens@osumc.edu.

Nisonger Trainee Stacie Pancoast

## NETWORK NEWS

### PA LEND Fellows and Faculty Help CHOP Launch its First Annual Homeless Health Initiative Regional Conference

Megan DiTizio, PA LEND Program Manager, The Children's Hospital of Philadelphia; Karen M. Hudson, MSW, HHI Program Manager, The Children's Hospital of Philadelphia

On November 12, 2007, The Children's Hospital of Philadelphia (CHOP) hosted its first annual Homeless Health Initiative (HHI) Regional Conference to address issues of homelessness and its impact on communities. A nationally-recognized "best practices" model at CHOP, the HHI provides medical and dental screenings for homeless children at three shelters in Philadelphia. In addition to basic healthcare, HHI provides training to shelter mothers and staff and works with other programs seeking to improve access to care for homeless families.



HHI Program Manager and LEND Social Work Faculty member Karen Hudson introduced the conference's mission and objectives and presided over the day's events. The Philadelphia City Council awarded HHI Leadership with a signed resolution recognizing their efforts in area shelters. Throughout the conference, medical, community, and local government leaders stressed the importance of empowerment and building diverse relationships to improve the lives of homeless children and families.

Karen Hudson was truly humbled by the participants' response to the entire day of events. "I am extremely pleased and proud to see LEND fellows demonstrating leadership in action," she said.

LEND fellows that contributed to the conference development, facilitation, and follow-up include:

- Melissa Berrios (Social Work) facilitated a roundtable discussion of creative therapies for children living in shelters. Participants utilized their experiences and knowledge to develop innovative and culturally effective ways to reach children and teens living in shelters. "This conference reaffirmed my belief that a leader is not merely someone who possesses a title of authority, but is a person who instills hope and inspires change," said Berrios.
- Beth Lohne (Family Studies) provided mentorship to a shelter mother who wished to convey her personal experience with homelessness at the HHI Conference. Beth assisted the mother in developing an oral presentation focused on her personal story and building community partnerships. Lohne noted that ongoing leadership training from LEND enabled her to encourage the mother to speak in front of a large, diverse audience.
- Neha Navsaria (Psychology) participated in conference planning and follow-up activities such as analyzing conference evaluations to improve future events. "I was thrilled by everyone's commitment to this event as well the diversity of community representatives involved in the planning process," said Navsaria. "Being part of the follow-up activities, I really saw the impact HHI had on attendees."
- Meagan Shank (Physical Therapy) facilitated a roundtable session focused on helping children with developmental delays that are living in shelters. The session included city leaders from several organizations dedicated to improving children's lives. "Collaboration and teamwork are essential," said Shank. "Everyone at this event is looking for better ways to work together and improve the lives of Philadelphia's homeless. That's powerful."



LEND Fellows and Faculty at the HHI Regional Conference at CHOP (L to R): Melissa Berrios, SW; Beth Lohne, Family; Karen Hudson, SW Faculty and Program Manager of HHI; Neha Navsaria, Psychology; Meagan Shank, PT. (Not pictured: Mira Manek, Healthcare Administration)



SW Fellow Melissa Berrios (center) facilitates roundtable discussion of creative therapies for children in shelter.



Family Fellow Beth Lohne (left) and parent mentee Kim Powell



PT Fellow Meagan Shank (upper right corner) listens as shelter staff considers developmental issues of children living in shelters.

## NETWORK NEWS

### University of Southern California LEND at Childrens Hospital Los Angeles Implements Interdisciplinary Training Clinic for Early Childhood Assessment

Marian E. Williams, PhD, Director, CHILD Center, USC UCEDD

The USC UCEDD has created an innovative partnership between our LEND training program and the Childrens Hospital Los Angeles (CHLA) Community Mental Health Program to provide state-of-the-art interdisciplinary training and services to young children with autism and other developmental disabilities. The Early Childhood Interdisciplinary Assessment Clinic provides comprehensive evaluations for children ages 3 to 5 years. Children are typically referred by physicians, school personnel, mental health providers, and parents, due to concerns regarding the child's difficulties with development, communication, learning, socialization, and/or behavior. Frequent referral questions include clarification of diagnostic issues including autistic spectrum disorders and mental retardation. Often families are already involved with multiple service systems and request assistance understanding their child's needs and how to access available services. Other times families are seeking help for the first time. The clinic evaluation and follow-up typically includes the following services:

- Comprehensive and in-depth interview with the parents/caregivers
- Formal assessments conducted by members of the interdisciplinary team, with discipline-specific measures
- Children referred to rule out an autism spectrum disorder are assessed using best practices guidelines developed by the California Department of Developmental Services in 2002 [www.ddhealthinfo.org/pdf/ASD\\_Best\\_Practice.pdf](http://www.ddhealthinfo.org/pdf/ASD_Best_Practice.pdf)
- Observation of assessments by interdisciplinary team and consultation from faculty and trainees in each discipline
- Needs assessment of family's needs, eligibility, and access to community resources
- Observations of the child in the community, such as at school, at early intervention program, and/or in home, and interviews with teachers and other key professionals
- Sessions with the parents/caregivers to discuss the assessment findings and recommendations in detail, answer questions, solicit input and together with the parents/caregivers, develop plan for continued services at CHLA and/or in the community
- Comprehensive written report, integrating input from all disciplines, provided to the family
- Follow-up consultation with referring provider and other professionals involved in the child's care, with permission and involvement from parents/caregivers
- Collaboration with the USC UCEDD Interdisciplinary Feeding Clinic for children with feeding difficulties
- Advocacy for the child/family to assist the family to access needed resources, including attendance at IEP and/or Regional Center meetings.

A key focus of the clinic is the interdisciplinary clinical process and leadership training of professionals from various LEND disciplines. All team members take on roles including serving as the primary care coordinator for a family. Leadership is provided by LEND faculty in the disciplines of psychology, communication disorders, and developmental-behavioral pediatrics, and the services are provided by trainees and staff in psychology, communication disorders, occupational therapy, family support, pediatrics, and case management.

A unique aspect of the clinic, most appreciated by families, is the creation of an integrated report (translated into the parents' primary language as appropriate), which includes information from each discipline in a coordinated way. This enables families and referring professionals to understand how the findings and recommendations from each discipline interact to create a full picture of the child and help to prioritize interventions. Another primary focus of the clinic is the provision of clinical services in a family-centered and culturally appropriate manner. The majority of the families seen in the clinic are from non-Anglo ethnic/cultural backgrounds, with the majority being Latino families who are either monolingual or bilingual Spanish speakers. Assessments of bilingual children include speech and language evaluations in both languages, to better inform the interpretation of other test results and recommendations for intervention.

For more information about the Early Childhood Interdisciplinary Assessment Clinic, contact Marian E. Williams, Ph.D., Director, CHILD Center, USC UCEDD, [mwilliams@chla.usc.edu](mailto:mwilliams@chla.usc.edu).





## NETWORK NEWS

### Oklahoma LEND and the Interdisciplinary Training Program in Child Abuse and Neglect (ITP) Collaborate on an Innovative Training Experience

**Dr. Tatiana Balachova, Co-Director, Interdisciplinary Training Program in Child Abuse and Neglect**

**Dr. Linda Wilson, Training Director, Oklahoma LEND Program**

Oklahoma LEND and the Interdisciplinary Training Program in Child Abuse and Neglect (ITP) are two interdisciplinary training programs in the Section of Developmental-Behavioral Pediatrics, Department of Pediatrics at the University of Oklahoma Health Sciences Center (OUHSC). Both programs collaborate each year to provide an innovative joint seminar session focused on issues of maltreatment related to children with developmental disabilities and their families. The session features Dr. Mark Wolraich, Oklahoma LEND Program Director and Dr. Barbara Bonner, Co-Director of the ITP Program. Dr. Wolraich and Dr. Bonner are nationally and internationally recognized leaders in their respective areas of Developmental Disabilities and Child Abuse and Neglect. Dr. Wolraich is the CMRI/Shawn Walters Endowed Professor of Developmental-Behavioral Pediatrics (DBP), DBP Section Chief, and Director of the OU Child Study Center. Dr. Bonner is the CMRI/Jean Gumerson Endowed Professor of Psychology, Director of the Center on Child Abuse and Neglect, and Associate Director of the OU Child Study Center.

The Oklahoma LEND-ITP joint seminar provides an opportunity for interdisciplinary trainees in both programs to learn together about current issues related to developmental disabilities and child maltreatment as well as the impact when both affect a child and family. Trainee teams including representatives from each program are assigned to participate in a case study review and discussion. This activity is followed by team reports, cross-team discussion, and evaluation of the review process. Interdisciplinary trainees this year represent the disciplines of Audiology, Developmental Pediatrics, Law, Nursing, Nutrition, Occupational Therapy, Parent-Family Issues, Psychology, Psychiatry, Public Health, Speech-Language Pathology and Social Work. The joint seminar is cooperatively planned by the Oklahoma LEND Training Director, Dr. Linda Wilson, and the ITP Co-Director, Dr. Tatiana Balachova. Two trainees from each program work together to co-facilitate the case study activity and subsequent discussion. The success of the joint seminar has included the opportunity to collaboratively focus on multiple perspectives related to the complex issue of maltreatment of children with developmental disabilities and their families.

For more information about the Interdisciplinary Training Program in Child Abuse and Neglect (ITP), contact Dr. Tatiana Balachova at [tatiana-balachova@ouhsc.edu](mailto:tatiana-balachova@ouhsc.edu) or at (405) 271-5700 ext. 42106. For more information about the Oklahoma LEND Program, contact Dr. Linda Wilson at [linda-m-wilson@ouhsc.edu](mailto:linda-m-wilson@ouhsc.edu) or at (405) 271-5700 ext. 45176.





## NETWORK NEWS

### South Dakota LEND: The Impact of a Baby's Early Environment upon Development

In recent years a number of articles have appeared in the medical literature discussing the potential adverse impact of environmental factors upon the subsequent neurodevelopmental state of very tiny premature infants. Noise, light, odor, and painful stimuli may all negatively affect the infant's condition and may have adverse long term neurodevelopmental consequences for the infant. Over the past three years, Dennis Stevens, MD, South Dakota LEND Director and an attending neonatologist at the Sanford Children's Hospital and Specialty Clinic in Sioux Falls, SD, has been conducting a multifaceted research investigation exploring the differences between the conventional open-bay neonatal intensive care unit (NICU), where all babies receive care in a single large room, and the new Boekelheide single-family room neonatal intensive care unit which opened in 2006. The new NICU has individual rooms where families can be with single infants or twins at any time. The facility was specifically designed so as to minimize adverse environmental factors such as high noise levels and constant exposure to artificial lighting.

The SD LEND Program leadership curriculum addresses the areas of leadership in clinical practice, research, advocacy and public policy. As a part of the curriculum each trainee completes an independent research project during their year of training. Dr. Stevens has involved both trainees and faculty in addressing a variety of questions which are a part of this investigation.

Examples of such involvement are as follows:

- Assessment of the reduction in noise exposure in the NICU – Audiology
- Assessment of financial impact and staff and parental satisfaction with care – Health Care Administration
- Staff job performance during night shifts – Occupational Therapy
- Staff walking/energy expenditure per shift – Physical Therapy
- Differences in feeding and weight gain in the two facilities – Nutrition
- Long-term developmental assessment – School Psychology.

This research is one of the most comprehensive investigations of the impact of the single-family room NICU design upon the outcomes of care which has been conducted to date.

The first results were published in the 2007 Journal of Perinatology under the following title:

The impact of architectural design upon the environmental sound and light exposure of neonates who require intensive care: an evaluation of the Boekelheide Neonatal Intensive Care Nursery

DC Stevens<sup>1,2</sup>, M Akram Khan<sup>1,2</sup>, DP Munson<sup>1,2</sup>, EJ Reid<sup>1</sup>, CC Helseth<sup>1</sup> and J Buggy<sup>3</sup>

<sup>1</sup>Sanford Children's Hospital and Speciality Clinic, Sioux Falls, SD, USA; <sup>2</sup>Sanford School of Medicine of the University of South Dakota, SD, USA and <sup>3</sup>Ellerbe Becket, Inc., Minneapolis, MN, USA.

The objective of this investigation was to show that environmental sound and light can be made to comply with the current recommendations for the design of neonatal intensive care unit facilities. The new Boekelheide Single-Family Room Neonatal Intensive Care Unit (NICU) at Sanford Children's Hospital was shown to have an ambient sound level of less than 50% of the previous facility (reduction from 42 to 37 dBA). In addition, the levels of illumination were significantly reduced in the new facility (6.4 vs 48.4 lux for minimum, and (357 vs 402 lux for maximum illumination). Uncontrolled high levels of both sound and light can have adverse long-term developmental consequences for the very tiny preterm baby. In a small group of neonates studied in both NICU environments, sleep time was increased by approximately two hours per day in the Single-Family Room NICU. Sleep is critical for sensory neurologic development in the tiny preterm neonate.



Picture of a Family Room in the new Boekelheide Neonatal Intensive Care Unit at Sanford Children's Hospital, Sioux Falls, SD. Accommodations for parents include a parent sleep area with privacy curtain, closet, desk with phone and answering machine and a refrigerator for breast milk storage.

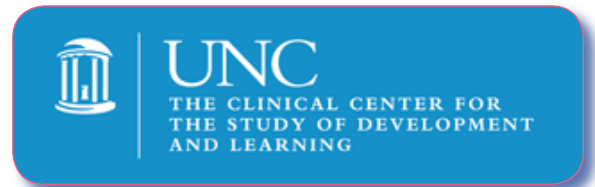
Photograph courtesy of George Heinrich, Minneapolis, MN.

## NETWORK NEWS

### New directions in psychology training and research at the UNC CDL

Jennifer Hiemenz, Clinical Center for the Study of Development and Learning, UNC Chapel Hill

In 2007, faculty members Kristine Kelsey (nutrition) and Jennifer Hiemenz (psychology) started a new clinical service at the UNC CDL to address picky eating behaviors in children with developmental disabilities. We are taking a family-centered educational and behavioral approach with parents who would like to get their children to eat a wider variety of foods in order to address any nutritional deficiencies that are noted through food diaries which are completed prior to each appointment. Our Nutrition and Behavior Clinic has followed approximately 5 children to date, and has helped to improve their eating behaviors. Earlier this year, Jennifer Hiemenz received a grant from the Mead-Johnson Children's Nutrition Small Grants program with Co-Investigator Leslie Fischer, PhD (Department of Nutrition, UNC School of Public Health) to look at the effects of choline and/or DHA fatty acid supplementation on cognition, language, and memory development in toddlers 18-24 months of age. In the fall of 2008, the CDL will introduce our Postdoctoral Residency in Pediatric Neuropsychology at the UNC CDL, directed by Jennifer Hiemenz. Our immediate goal is to obtain accreditation from the Association of Postdoctoral Programs in Clinical Neuropsychology (APPCN) by the end of the calendar year. Our first postdoctoral resident in this program will be Phil Icard, who is our CDL intern for 2007-08. As there are few postdoctoral residencies in this area that also have an emphasis on developmental disabilities, this will bring the CDL additional recognition on the national level as an exceptional training program.



### NEWSWEEK Magazine Article Authored in part by LEND Faculty

Kerim Munir, ScD, MD, Psychiatrist at Children's Hospital Boston (LEND) and Harvard Medical School



#### How to Solve Three Puzzles

NEWSWEEK, Jan 21, 2008 Issue

New knowledge and sophisticated diagnostic techniques are helping doctors recognize early signs of autism, Alzheimer's disease and heart problems in women. Harvard experts report on the advances that are giving patients hope.

Read the full article here: <http://www.newsweek.com/id/91658>.

Photo by Martina Hoogland  
Ivanow for Newsweek

### H.R. 3995: Introduced by Representative Frank (D-MA)

Kim Musheno & Tammie Pickelsimer, AUCD

Congressman Barney Frank, a Democrat from Massachusetts introduced a bill (H.R. 3995) in the last Session of Congress that would limit the ability of protection and advocacy systems to protect individuals with developmental disabilities in institutions. Specifically H.R. 3995 would prevent any entity receiving federal funds to file class action lawsuits against an intermediate care facility for the mentally retarded (ICFs/MR) on behalf of any resident of such facility unless the resident (or representative) has the opportunity to "opt-out". The Voice of the Retarded (VOR), a parent group and major supporter of the bill, believe that state Protective and Advocacy (P&As) have filed unnecessary lawsuits that directly led to the downsizing and closure of public and private ICFs/MR.

AUCD, along with many other organizations, considers the bill to be harmful to people with disabilities because it limits the ability of advocates to protect people in ICF/MRs from abuse and neglect. By having broad authority to pursue appropriate remedies, the Protection and Advocacy system has been instrumental in ensuring the protection of the rights of people with developmental disabilities. Second, society, the courts, and the Congress have been moving away from institutionalizing individuals with developmental disabilities to create supports and services that allow these individuals to live full and productive lives in the community. This bill not only does not support community living, but also restricts the rights of individuals with developmental disabilities by allowing those that would prefer to speak on behalf of individuals with developmental disabilities to have the final say, even if different than the individual's own desires.

Currently, the bill has 13 cosponsors and has been referred to the House Committee on the Judiciary. AUCD is working along with the Consortium for Citizens with Disabilities to educate Members of Congress about the harmful effect this bill would have on the rights of individuals with disabilities. Additional information can be found at the NDRN Civil Rights website: <http://www.ndrn.org/policy/civrght/>.

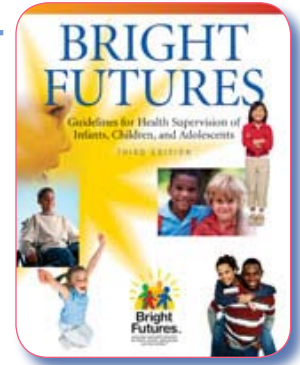
## RESOURCES

### Bright Futures Guidelines Release

Bright Futures and the American Academy of Pediatrics are pleased to announce the release of the Bright Futures Guidelines for Health Supervision of Infants, Children, and Adolescents, Third Edition. Bright Futures is a developmentally-based national health care promotion and disease prevention initiative designed to address children's health care needs in the context of family and community.

#### About the Guidelines

Bright Futures Guidelines and other materials help pediatricians and other health care professionals provide the best care possible for children and families. The 3rd edition of the Bright Futures Guidelines has integrated the American Academy of Pediatrics' (AAP) Guidelines for Health Supervision, resulting in the official guidelines for pediatricians.



Organized for quick, easy access to the information you want, the Bright Futures Guidelines feature the following:

- Part 1 includes 10 chapters on key themes that recur in each stage of child development, ie, mental health, healthy weight, healthy nutrition, family support, child development, physical activity, oral health, healthy sexual development, safety and injury prevention, and community relationships and resources.
- Part 2 provides both health supervision guidance and anticipatory guidance for the 31 recommended health supervision visits from 0-21 years.

The Guidelines reflect and include the newly revised AAP Periodicity Schedule as a poster available for tearing out.

Learn more about Bright Futures and get other materials at [www.brightfutures.aap.org](http://www.brightfutures.aap.org).

### MCH Leadership Skills Development Series (MCHLDS)

[www.jhsph.edu/wchpc/MCHLDS](http://www.jhsph.edu/wchpc/MCHLDS)

The MCHLDS is made up of leadership skills training modules that allow you to implement your own leadership skills training program—in your own time frame, on your own turf, with easy-to-use materials available on the web free of charge. The modules bring leadership concepts to life in an MCH context through a mix of video, interactive group discussion questions and exercises, case study, and individual self-reflection and planning exercises.

- Module 1: Tapping Into Your Leadership Potential
- Module 2: Creating Clarity and Shared Vision
- Module 3: Building And Supporting Teams
- Module 4: Negotiation and Conflict Resolution (available Spring, 2008)

By providing access to fundamental concepts of leadership, with examples and exercises specific to the MCH context, we hope to empower MCH professionals and students—emerging leaders at all levels of career and organizational development—to respond in new ways to the daily challenges of work and commit new energy to the achievement of MCH goals.

The Maternal and Child Health Leadership Skills Development Series is a publication of the Women's and Children's Health Policy Center at the Johns Hopkins Bloomberg School of Public Health.

To learn more, visit [www.jhsph.edu/wchpc/MCHLDS](http://www.jhsph.edu/wchpc/MCHLDS).



### The Spectrum of Developmental Disabilities

March 31-April 2, 2008



The Johns Hopkins University School of Medicine and the Kennedy Fellows Association/Kennedy Krieger Institute is sponsoring a continuing education course, "The Spectrum of Developmental Disabilities," to be held March 31-April 2, 2008, at the Johns Hopkins University School of Medicine Thomas B. Turner Building. This interdisciplinary course, now in its 30th year, will focus on Neurobehavioral Syndromes and focus on the mechanisms, evaluation, diagnosis, and management of behavioral disorders in people with developmental disabilities. Please see the following link to obtain a brochure and to register: [http://www.hopkinscme.edu/CourseDetail.aspx?course\\_code=80016765](http://www.hopkinscme.edu/CourseDetail.aspx?course_code=80016765).



## EVENTS

### Three UCEDD/LENDs Partner to Offer Conference: Children in Foster Care: Development, Health, and Well-being

**A day long conference to share successful models and to work on challenges to optimal development, health and well-being of children in foster care**

Friday April 11, 2008, 8:30 AM to 4 PM

Cedarwood Hall, Westchester Institute for Human Development & the School of Public Health at New York Medical College, Valhalla, NY

Who should attend:

- Professionals who direct programs for children in foster care and their families
- Parents with experience as foster parents, adopting from foster care, or having a child return from foster care
- Representatives from state and local agencies involved with children in foster care and their families

Keynote presentations include *Promoting the Healthy Development of Young Children in Foster Care: Challenges and Strategies* by Sheryl Dicker JD, Senior Advisor, National Center on Children in Poverty; and *Healthy Children in Foster Care: An Attainable Goal*, by Steven Blatt MD, Associate Professor of Pediatrics, Upstate Medical University. Afternoon workgroups co-led by professionals and parents to share what works and to grapple with the challenges in relevant areas.

The conference was developed as part of the ongoing collaboration between the three University Centers for Excellence in Developmental Disabilities (UCEDD) and Leadership Education in Neurodevelopmental and related Disabilities (LEND) Programs in New York State (listed below), the Developmental Disabilities Planning Council; and the Commission on Quality of Care and Advocacy for Persons with Disabilities Protection and Advocacy Program. Representatives from other key state agencies have served as conference planning partners. This conference program has been endorsed by NY Chapter 3, American Academy of Pediatrics.

- Rose F. Kennedy UCEDD and LEND Program, Albert Einstein College of Medicine, Yeshiva University, Bronx, NY
- Westchester Institute for Human Development UCEDD and LEND Program, in affiliation with the School of Public Health at New York Medical College, Valhalla, NY
- Strong Center for Developmental Disabilities UCEDD and LEND Program, University of Rochester; Golisano Children's Hospital at Strong; Rochester, NY

For registration information, contact Leigh Colby at [lcolby@wihd.org](mailto:lcolby@wihd.org) or 914-493-8175. A number of travel stipends are available for parents participating in the conference. Registration fee: \$40 for professionals, \$10 for parents

### Leadership, Legacy, and Community: A Retreat To Advance Maternal and Child Health Scholarship and Practice

July 16-18, 2008

Hosted by the University of Illinois at Chicago (UIC) MCH Program



Leadership, Legacy, and Community is a new professional development Retreat designed for interdisciplinary, junior and senior MCH practitioners and scholars. In this Retreat, we will convene to discuss, make recommendations, and identify strategies to address major evidence-based challenges we face in MCH (what to do when there is no intervention for an important problem, what to do if our intervention works but not for the intended problem, what to do if our intervention doesn't work for all populations, and what to do if we have a great intervention but no investment in it). We will also engage in training designed to further develop our leadership skills no matter what stage of career we are new (new to the workforce through been in the workforce 20+ years) or type of career (academic or practitioner).

Finally, and perhaps most importantly, we will lay the foundation for building an MCH community of academics and practitioners that draws on the energy and idealism of junior MCH professionals and the energy and wisdom of senior MCH professionals in both academic and practice settings. When these four groups gather together to collectively address the challenges we face in our daily struggle to improve MCH, we believe the synergistic impact will result in new energy, ideas, and collaborations that will help motivate and inspire us as we move forward.

July is a great time to be in Chicago! For additional information about Leadership, Legacy, and Community, visit our website at [www.uic.edu/sph/mch/continuing\\_education.htm](http://www.uic.edu/sph/mch/continuing_education.htm), or contact Kristina Risley ([kyrisley@uic.edu](mailto:kyrisley@uic.edu)) or 312.996.2875.

## TRAINEE CORNER

### Trainees: Take the Lead!

Terri Abrams, 2007-2008 AUCD Virtual Trainee

One of the best parts of the political system here in the United States is that we, the citizens, have the right and the ability to impact policy.

There are a good many folks who choose not to participate in this privilege. They could register and vote, but they don't.

There are other folks who read up on issues, converse about them where they live, and vote regularly.

Then there is the group that goes further—they carry their voices, ideas, needs, and desires directly to their legislators. These folks are LEADERS.

LEND trainees, these folks are you. You are the people who applied and were chosen for LEND training. You have been reading and discussing disability issues, learning to function in cross-disciplinary settings, and learning to impact systems.

You are not the stay home and complain crowd, or the "I vote" crowd.

The Disability Policy Seminar takes place March 2- 4 in Washington, DC. This is a seminar of leaders. Folks come from around the country to learn legislative advocacy skills, to learn the ins and outs of the current legislative issues, and to take that knowledge "to the Hill."

Last year Bobbie Silverstein trained us all on the process of legislative visits—he was a long-time staffer for Sen. Tom Harkin and helped write the ADA. I sat in the morning with people from Portland, OR, and had lunch with the Executive Director of UCP in Detroit, MI. I attended the AUCD reception where I met directors and trainees from programs from around the country. The trainees went to dinner together after the reception and shared tapas and contact information.

When I made legislative visits with fellow New Yorkers we spoke mostly with staff people in each of the offices, but I actually ran into (yes, literally) Hon. Thomas Reynolds—the Representative from my district.

I came home exhausted, far more conversant on legislative issues, and knowing that I had made a difference!

What will you be doing this March 2-4? I hope to see you in Washington, DC.

To learn more about the Disability Policy Seminar, visit [www.aucd.org](http://www.aucd.org). Read trainee summaries and view pictures from the 2007 event on the trainee page of [www.aucd.org](http://www.aucd.org).



### Reflections from the NICU

Thomas Verstynen, Public Administration Graduate student, NM LEND

**Editors Note: The following is an excerpt from a full-length article. Read the full article online in the trainee section of [www.aucd.org](http://www.aucd.org).**

Billy-Ruben? What is that? Sounds like some sort of promotional sandwich you could order from Applebees.

I sat in my seat, surrounded by numerous healthcare students and professionals, each of them brilliant in their own fields, perplexed by the term that was just thrown into the discussion. I looked up and made eye contact with Joan Bradley, one of the nursing faculty for the New Mexico LEND program. Even though I desperately tried to conceal it, I knew she could tell that I was confused.

"Do you know what that term means?" she asked gently.

As a graduate student in Public Administration I have found that one of the difficulties I have during our weekly discussions is the medical jargon that is used so commonly. Between biliruben, balcofen, and myocardial infarction, I feel like I am playing Scrabble and it is my turn to change the letters I have before me into actual English.

As part of our curriculum for the New Mexico LEND, each of us has to visit the Neonatal Intensive Care Unit, NICU, at the University of New Mexico Hospital. With much of the group being nurses, doctors, and other types of health personnel, many of them had already visited the NICU. They knew what they would encounter. While I felt like I had a good idea of what I would come across, nothing prepared me for what I would see, what I would feel, and what I would walk away with after my experience...

One of the reasons why I applied to the New Mexico LEND was that I wasn't so sure if I wanted to get into the field of health care policy. I am also very interested in other things such as criminal law, environmental policy, and international relations. I applied to the LEND project to see if health care is something I actually want to be a part of. While I am still undecided with what I will do for the rest of my life, and am predicting I will be for the majority of my life, the NICU experience unquestionably gave me a new perspective on health care policy and how it affects us all. It helped me realize that even I, the lonely bureaucrat, might be able to benefit these babies and their families...

Read the full article online in the trainee section of [www.aucd.org](http://www.aucd.org).



## TRAINEE CORNER

### AACPDM: An Energizing Meeting!

Necia Davis, PT, CDRC Pediatric Physical Therapy Resident, Oregon LEND Trainee

This past fall I attended the annual meeting of the American Academy for Cerebral Palsy and Developmental Medicine (AACPDMD) held in Vancouver, British Columbia. Let me tell you, it was an incredibly inspiring experience! AACPDMD is a multidisciplinary scientific society devoted to the study of cerebral palsy and other childhood onset disabilities, to promoting professional education for the treatment and management of these conditions, and to improving the quality of life for people with these disabilities. There are many reasons the meeting was truly an inspiring, exciting, and energizing experience for me.

Unlike so many of the other professional association meetings and continuing education courses I have attended, the AACPDMD meeting draws professionals from many different disciplines and specialties rather than from only one or two disciplines. The meeting and its scientific program are available to any registered professional who might be interested. The seminars, instructional courses, and platform paper presentations are not usually so discipline-specific that professionals of many fields cannot learn and gain from them. This adds a really great educational and collaborative element to a level that I have not otherwise experienced at a meeting or course. The professionals who are members of the Academy present at the conference, and also those who simply choose to attend the meeting tend to be amongst the best of the best in their disciplines from around the country and even the world. It is great to be amongst such respected and sharp company!

With such knowledgeable company, as you would expect, comes presentations about treatments, surgeries, new findings, and the like, which are truly cutting edge. As a recent graduate, a physical therapy resident, and a LEND trainee – very new in my field – some of what was discussed went right over my head. And, yet, so much did not! That was exiting in and of itself. This aspect of the meeting inspires me to keep up with the latest information available, and even to participate in new research and studies to further advance our field. I love that this kind of education makes it nearly impossible to stay narrow-minded or stuck in professional “ruts.” A specific course that stands out to me was one about all the latest and most effective orthopedic, medical/pharmacological, and therapeutic techniques, which, in combination, are being used to treat children with cerebral palsy. This course has helped me to see the “bigger picture” as I treat kids with cerebral palsy, and as a result, will help me to be a better therapist.

There are many more reasons why the AACPDMD experience was meaningful to me, but the last one I will mention is the time set aside for networking amongst professionals. I met so many great therapists, physicians, educators, and others that I hope to collaborate with in the future. This alone made the meeting worthwhile, as it allows sharing of resources, knowledge, and makes working toward common goals more efficient and productive. A central theme of my LEND training has been the importance of the interdisciplinary approach, and the AACPDMD meeting reinforced that concept for me in a very powerful way.

In short, this was a meeting I will never forget, and I hope many LEND trainees around the country would have the good fortune to enjoy such a positive professional experience. I eagerly became a member of the Academy, and encourage all LEND trainees to do the same. This is a membership that will expand any professional's skills, knowledge, and opportunities. I look forward to attending the AACPDMD annual meeting again in the years to come!



*"The American Academy for Cerebral Palsy and Developmental Medicine is a multidisciplinary scientific society devoted to the study of cerebral palsy and other childhood onset disabilities, to promoting professional education for the treatment and management of these conditions, and to improving the quality of life for people with these disabilities."*

Learn more about AACPDMD online at [www.aacpdm.org](http://www.aacpdm.org).





ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES

RESEARCH, EDUCATION, SERVICE

## LENDLinks

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### Submissions

Items of interest to LEND programs may be submitted for consideration to cpariseau@aucd.org. High quality electronic images are encouraged.

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

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## Disability Policy Seminar

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Advancing Disability Policy in an Election Year, the theme for the 2008 Disability Policy Seminar, will offer a pragmatic view on the unique challenges and opportunities facing the Congress and White House as the 2008 political campaign proceeds.

In November of 2008 Americans will cast votes for a new President, a third of the Senate, and the entire House of Representatives. The Democrats will seek to expand their present thin majority in both houses of Congress while Republicans fight hard to regain lost ground. With bipartisanship an increasingly elusive goal for most public policy issues these days, we will explore effective strategies to obtain support from both sides of the aisle for disability issues.

Together, The Arc of the United States, United Cerebral Palsy (UCP), the Association of University Centers on Disabilities (AUCD), the American Association on Intellectual and Developmental Disabilities (AAIDD) and the National Association of Councils on Developmental Disabilities (NACDD) will look to our extensive grassroots networks to advocate in a bipartisan manner for national public policies promoting the full inclusion of people with disabilities in our society.

On Sunday, March 2, at 9:30 a.m., participants will begin two days of in-depth, intense public policy discussions/presentations that end on March 3 at 6:00 p.m. On March 4, we will take our unified message to Capitol Hill.

What will we be talking about at the Seminar and lobbying for on Capitol Hill? We expect the following public policy issues will take center stage:

- Budget and Appropriations
- Entitlements
- Developmental Disabilities Act
- Health
- Housing
- Social Security
- Americans with Disabilities Act
- Employment

Capitol Hill staff and our nation's leading public policy experts, disability advocates and association leaders will be on hand to address these and other issues.

*For more information including registration, logistics, and background materials, visit [www.aucd.org](http://www.aucd.org).*

