



News from AUCD

Happy Spring!

AUCD had a strong presence as a co-sponsor of the Association of Maternal Child Health Programs' (AMCHP) 2004 Annual Conference February 28-March 2 in Washington, D.C. First, the **Spring LEND Director's Meeting** was held over two days, providing LEND programs with valuable updates from MCHB and finding new ways for AUCD to continue to support the LEND network in the coming years. Second, **Health Administration** was the focus of this year's LEND Discipline Meeting. Over 40 staff and trainees from LEND programs came to hear more about the importance of Health Administration (HA) as a LEND discipline and to brainstorm ways to incorporate this discipline into LEND training. Outcomes of the meeting are the development of a workgroup, a new HA listserv, and a website resource listing for HA. Third, AUCD was very excited about the **Joint Meeting of four MCHB training programs**. Over 95 faculty and staff from LEND, LEAH, PPC and SPH (Leadership Education in Adolescent Health, Pediatric Pulmonary Centers, and Schools of Public Health) gathered for a morning of cross-program collaboration in the area of transition planning for youth with disabilities. We will continue exploring this new partnership by talking often and meeting again. Fourth, a number of LEND Directors, trainees and staff joined AMCHP representatives in **visiting members of Congress**, educating staffers on the importance of the Title V Block Grant. Visits were made to the offices of a number of key Appropriations Committee members including Chairman Young (R-FL), Chairman Specter (R-PA) and Ranking Member Harkin (D-IA). THANK YOU to everyone who attended these meetings, presented valuable information and visited with Hill staff during the weekend of AMCHP's Annual Conference!

To view **notes and photos** from any of these meetings, as well as look through resources, visit "Events" on AUCD's **website**, http://www.aucd.org/aucd_events.htm.

Nearly 500 individuals with disabilities, family members, trainees and professionals attended the **2004 Governmental Affairs Seminar** March 21-22 - the largest attendance at this event ever! Participants were briefed on current legislative and regulatory issues by the

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News from our Partners

MCH Collaborative Network at UAB

*Nancy Woolridge, MS, RD, LC & Gina E. Harris, LCSW, DCSW,
Alabama UCEDD, LEND & PPC*

UAB is currently the only institution in the nation to have LEND, LEAH, PPC and SPH training programs.

Currently the University of Alabama at Birmingham (UAB) is the only institution in the nation to hold all four major types of interdisciplinary, long-term training grants awarded by the Maternal and Child Health Bureau (MCHB). Each program has a specific focus, but all place an emphasis on interdisciplinary leadership training and are mandated to have regional and national impact through various activities. The four MCHB-funded SPRANS projects are:

- Leadership Education in Adolescent Health (LEAH) – **Marsha Sturdevant, MD**, Project Director – LEAH prepares professionals from a variety of health care disciplines to be leaders in adolescent medicine in clinical care, research, public health policy and advocacy.
- Leadership Education in Neurodevelopmental Disabilities (LEND) – **Alan Percy, MD**, Project Director – The LEND program provides interdisciplinary leadership training to health care professionals in a variety of disciplines to improve the health of children and youth who have or who are at risk of developing neurodevelopmental disabilities.
- Pediatric Pulmonary Center (PPC) – **James Hagood, MD**, Project Director – The PPC develops leaders who will improve the health of children with respiratory conditions, such as asthma and cystic fibrosis, through the provision of family-centered care.
- MCH Graduate Training Program, School of Public Health, Department of Maternal and Child Health – **Greg R. Alexander, MPH, ScD**, Project Director – This program prepares graduate students (MPH and DrPH) for careers in MCH epidemiology and analysis, MCH program administration, management and practice, MCH policy development and advocacy, and international MCH.

The faculty members of the MCHB-funded training projects at UAB have collaborated in training, research, and providing services to clients and their families. By working together, the faculty members are able to share resources and tailor programs to better meet the needs of long-term trainees. In August 2002, the UAB MCH Collaborative Network was created,

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News from AUCD

To view notes and photos from recent LEND meetings, visit the Events section of www.aucd.org!

sponsoring organizations, Hill staff and Administration officials. Participants also traveled to Capitol Hill to talk with their Members about disability related legislative issues, such as the New Freedom Initiative, Medicaid, transportation, assistive technology and employment. Read issue briefs developed for the GA Seminar at http://www.aucd.org/aucd_legisaffairs.htm.

In April, MCHB staff, AUCD staff, and a large number of LEND faculty joined staff from other MCHB training programs in Seattle, where University of Washington MCH programs hosted an **MCH Working Conference: The Future of Maternal and Child Health Leadership Training**, which summarized past leadership conferences and explored the future of interdisciplinary leadership training. The conference's intent to provide a forum for national MCH leaders to share experiences, learn from one another, and form professional relationships to enhance attendees' effectiveness as leaders and mentors of future leaders was accomplished through two days of formal and informal presentations and workgroups. Keep looking for conference reports and suggestions from both AUCD and MCHB.

Remember, the next LEND Links will be distributed in September. Please send your submissions to Crystal Clement (clement@aucd.org) by August 9, 2004.

News from our Partners

“Moving On” Transition Program

*Craig Becker, MSSW & Darci Pfeil, NP
Wisconsin PPC*

Transition is spot-lighted in literature, conferences and in federal guidelines as a priority to be addressed. As would be expected, transitioning from pediatric to adult care has become a focus in Cystic Fibrosis (CF) centers around the world.

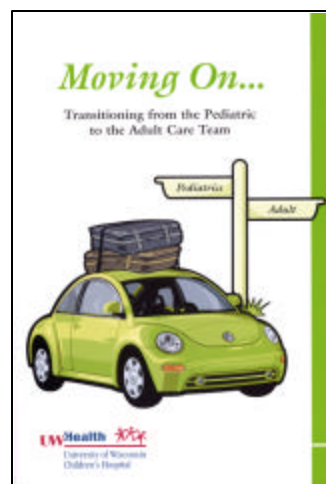
Healthy People 2010 established the goal that all young people with special health care needs will receive the services needed to make the necessary transition to all aspects of adult life (Centers for Disease Control and Prevention 2000). Just as the Individuals with Disabilities Education Act of 1997 requires a plan for education transition, so too there needs to be a plan for health care transition (Pediatrics 2002). The questions that remain are: “How do we effectively transition young adults?” “Do we agree on how transition will be implemented and at what age is best?” “Are we as passionate about transition as the literature would suggest?”

We surveyed 147 health care professionals at the University of Wisconsin Children’s Hospital and Clinics and received some eye-opening feedback. We received only a 20% response rate. Interestingly, it was clear that transition was an important issue to those responding; however, there was not an overwhelming consensus regarding any of the specifics. We learned there was little agreement on the age of transition, who should be involved, what barriers exist and what guidelines would be helpful.

The results of our survey prompted us to create a transition program that addressed transition issues from a developmental perspective. This program was designed to increase participation and responsibility of the pediatric patients at six key stages in their developmental cycle. At each stage there is an overview of what to expect. There is also an educational checklist to help patients and families learn more about CF. The overall goal is to develop the skills needed to help young adults build confidence and increase independence as they take charge of their life and CF cares.

The program begins at age eight when patients begin to learn the basics of CF, medication and therapies. The program progresses toward completion approximately 10 years later, with the successful transition to adult care. Included in the program is a section on what family members, adolescents and the health care team can do to prepare for transition. It also highlights common questions and concerns about transition and provides a summary checklist entitled “How do you know when it is time to transition?” The program addresses how

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LEND Program Highlights

The Human Experience of DisABILITY

Janet S. Wilson, PhD, RN
Oklahoma LEND

For the past six years, the University of Oklahoma Health Sciences Center, College of Nursing, has offered a 2credit required course to both undergraduate and graduate nursing students entitled *The Human Experience of DisABILITY*. The course, the first in the country, developed and taught by **Dr. Janet Sullivan Wilson** and a team of nursing faculty, is offered in the classroom setting and via the internet. The need for such a course was based upon research which strongly suggests that although many healthcare providers regularly care for the almost 34 million people with disabilities, professionals may not be as helpful as we think. "Families of children with developmental disabilities have reported that caregivers often do not take their concerns seriously or understand their children's problems. Other families have reported that they felt caregivers frequently did not listen to them, showed a lack of respect, and ignored their expertise in managing situations." (Wilson and Merrill, 2002, p89)

With this in mind, Dr. Janet Wilson, Oklahoma LEND Core Faculty in Nursing, **Jan Moss**, Oklahoma LEND Core Faculty in Parent and Family Issues and **Chuck Roberts**, Oklahoma LEND Core Faculty in Self Advocate Issues began an interdisciplinary partnership to extend the course across disciplines at the University of Oklahoma Health Sciences Center and via internet to the LEND network. The content of the course is unique in that it is mostly from the perspective of people with disabilities which stresses "abilities," rather than a problem-focused medical perspective. A packet of readings elucidates the major issues people with disabilities have defined as important to their everyday lives. Also, conceptual issues of race, class, gender, culture, historical context, and sexuality are theoretical "threads" woven into each learning module which contextualizes the disability experience and literature for the students. Other unique features of the class are:

- The class is taught to over 200 students at five different learning sites across the state of Oklahoma.
- The class is designed with flexible "learning modules" that contain a potpourri of learning activities which can be adapted for in-class and/or internet delivery.
- Students contract with a person with a disability and must write a paper describing the major disability issues "from the perspective of the person with the disability." This means that the student and the person they have contracted with are partners in the paper, rather than "subject" and writer. At the end of the semester each student presents his or her paper to the group with a creative learning device or tool (brochure, video, poster, etc.) .
- Person first language is taught early in the course and curriculum. The expectation is that all students' verbal and written communication in the course and in subsequent courses will use person first language.
- Pop culture films (e.g., *The Other Sister*, *Passion Fish*, *Lorenzo's Oil*, etc.) are combined with documentaries (e.g., *Without Pity*) to stress the course concepts and contrast with current research.
- Current events are encouraged in "show and tells" to compare with the research and literature. For example, a 1998 court injunction allowed Casey Martin, the professional golfer, to ride in a golf cart during the PGA Nike tour. Students questioned the concept of "reasonable accommodation" according to the American Disabilities Act and for the rest of the semester this case became the springboard for discussion for the many issues that face people with disabilities today.
- Two-hour "training sessions" in assistive technology and visual services award certificates that students can include on their resumes.
- Online cartoons by John and Claire Lytle (<http://www.dizabled.com/>) are used to demonstrate potential and strength based living skills and styles.
- Inclusion of clients: clients often come to the student presentations or submit materials they have developed or found helpful. For example, one client wrote a list, "The 12 Important Items to Remember," for healthcare providers. This is now included in the course reading packet.

Beginning qualitative and quantitative data suggest this course makes a difference in health care professional attitudes towards people with disabilities. Ultimately, the goal is that every

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**Ultimately,
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LEND Program Highlights

Virginia LEND Research and Poster Fair

Janet H. Willis, MPH, RD
Virginia LEND

As an assignment for the Spring 2004 Childhood Neurodevelopmental Disabilities course, the trainees in the Virginia LEND program developed research posters and presented them at a poster fair in March. Each trainee identified an evidence-based research question or topic related to childhood developmental disabilities or chronic conditions. They completed a literature search and identified 3-5 current data-based papers in peer-reviewed publications related to their topic. With guidance from a faculty mentor, trainees developed a poster and abstract describing the objective, background, results and conclusions. The posters were displayed and presented at an evening poster fair attended by faculty and trainees. Below is a list of topics presented.



2004 Poster Topics:

- What is the Relationship Between Inclusion and Social Integration for Children with High Incidence Disabilities by **Carol Broaddus**, Special Education trainee
- Developmental Outcomes of Extremely Low Birth Weight and Very Premature Infants by **Patricia Cooper**, Occupational Therapy trainee
- The Diagnostic Evolution of Rett Syndrome by **Rebecca Yee**, Genetic Counseling trainee
- Constraint-Induced Movement Therapy: A Beneficial Treatment for Children with Hemiplegic Cerebral Palsy by **Heather Walling**, Physical Therapy trainee
- The Efficiency of Botulinum Toxin A in the Treatment of Children with Spasticity Associated with Cerebral Palsy by **Aaron Perkins**, Physical Therapy trainee
- Stress in Parents of Children with Autism by **Melinda Moore**, Psychology trainee
- Auditory Processing Disorders in School-Aged Children by **Melissa Harden**, Occupational Therapy trainee
- Common Diagnosis in Pediatric Dentistry: Cleft Lip and Palate by **Jennifer Dixon**, Pediatric Dentistry trainee
- Dental Issues in Ectodermal Dysplasia by **Arshia Shingler**, Pediatric Dentistry trainee
- CHARGE Association: Clarifying the Diagnostic Criteria and Teaming Necessary for Intervention by **John Eisenberg**, Special Education trainee
- Down Syndrome and Celiac Disease: Testing Early to Prevent Long Term Complications by **Catherine Roberts**, Nursing trainee
- Psychosocial Adjustment Outcomes of Siblings of Youth with Chronic Conditions by **Melissa Bellin**, Social Work trainee
- Pediatric Dental Issues by **Holly Hall**, Pediatric Dentistry trainee
- Benefits of Inclusive Education for Students Served in Special Education and General Education by **John Richmond**, Special Education trainee

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The Human Experience of DisABILITY

caregiving professional will not only care for people with disabilities, but care about them as well.

Wilson, JS & Merrill, AS (2002). Teaching students to care for and about people with disabilities, Nurse Educator, (27)2, 89-93

For more information about The Human Experience of DisABILITY and Oklahoma LEND, contact:

Janet Sullivan Wilson, PhD, RN, Oklahoma LEND Core Faculty in Nursing
Oklahoma LEND Program; Post Office Box 26901, ROB 342; Oklahoma City, Oklahoma, 73190; Janet-wilson@ouhsc.edu

LEND Program Highlights

“Babies Can’t Wait”

RFK UCEDD educates court personnel about the lives of children in foster care

Arnold Birenbaum, PhD., New York (Bronx) LEND

Chaired by Judith Kaye, Chief Judge of the State of New York, the Permanent Judicial Commission on Justice for Children was created to address the problems of children whose lives are affected by the New York State court system.

Currently, more than 50% of infants and young children in foster care have developmental delays and/or significant emotional or behavioral problems; more than half of these young children have serious physical health problems. Many do not receive adequate health or mental health care, according to **Dr. Susan Chinitz**, Director at the RFK UCEDD’s Early Childhood Center.

The “Babies Can’t Wait” project of the Judicial Commission highlights the particular health and developmental needs of young children in foster care, and makes it the responsibility of all decision makers in the child welfare and court systems, including family court judges and children’s law guardians, to inquire about the child’s health and developmental status, and, when appropriate, to connect infants and parents to evaluation, intervention and support services. The faculty of the Children’s Evaluation and Rehabilitation Center at the RFK UCEDD developed the “Babies Can’t Wait” curriculum and furnish the instruction. For more information, please contact Susan Chinitz, Psy.D. at Schinitz@aol.com.



Kansas UCEDD Mentors Community in Child Development

*Lisa R. Hull
Kansas LEND*

In collaboration with the Mid-America Regional Counsel, the Kansas Developmental Disabilities Center (DDC) will participate in the Early Learning Opportunities Act (ELOA) aimed at improving childcare in the greater Kansas City area. The DDC will dispatch an interdisciplinary team of service providers and trainees to perform 30 site visits to child care centers over the next ten months. Each site visit will include education about typically developing children as well as identifying developmental delays/disabilities and behavioral concerns in young children. **Dr. Chet Johnson**, who has committed his career to improving the quality of life for children, commented upon the importance of the ELOA Project. “Unfortunately, the general public is not very knowledgeable about child development. A child with a developmental delay/disability maybe seen as an obstinate child or thought to be able catch up and the delay/disability remains unidentified.”

These education sessions are aimed at Childcare Center Directors, childcare providers, and parents.

An interdisciplinary team from the Developmental Disabilities Center served as a panel to childcare providers at El Centro, a non-profit organization dedicated to improving the lives of Kansas City’s Hispanic residents. The DDC team presented criteria for identifying developmental delays and disabilities as well as dispelling myths of cause and empirically validated practices. “We anticipate a long term, educationally reciprocal relationship with El Centro,” stated **Jacqueline Hampton**, Intake Social Worker and Chair of the Community Outreach Committee. “We’d like El Centro to educate our professional staff and trainees on Hispanic culture and serve as a vehicle for the DDC to reach out to underserved populations.”

DDC’s participation in the ELOA project as well as partnering with El Centro adds a dimension to our training component. **Dr. Matt Reese**, Training Director asserts, “These relationships present a unique opportunity for our trainees to learn how to interact within the community and have a part in effecting systems change in the way we care for our children.”

*“We anticipate a
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relationship...”*

LEND Program Highlights

Living With Nature

Catherine Alguire, MLA, OTR/L and Stacy Springer, BS, OTS
North Carolina LEND

Living With Nature is a new project led by **Catherine Alguire, MLA, OTR/L**, the Occupational Therapy Section Head at the NC-UCEDD & LEND, the Clinical Center for Study of Development and Learning (CDL) at the University of North Carolina at Chapel Hill. *Living With Nature* is an innovative residence-based intervention model that incorporates principles of self-determination, horticulture therapy and occupational therapy through supported choice making and participation in nature-related activities. The goal of the program is to enhance personal causation and targeted health factors in older adults with mental retardation/ developmental disabilities (MR/DD) who are living in supported group residential environments.

The project is being implemented at Spring Glen, the first supported living retirement center in North Carolina for people with developmental disabilities aged 50 or older, which opened in Fall 2003. Residential Services, Inc. (RSI), a not-for profit agency based in Chapel Hill, developed and manages Spring Glen and other supported living residences in Orange County; it is one of the two community partner agencies involved in the project. Horticultural therapists at the North Carolina Botanical Garden (NCBG) have been the other active collaborators on the project and related activity curriculum.

The *Living With Nature* project has yielded a myriad of leadership opportunities for CDL LEND trainees. **Lynn Porter, BA, OTS**, the 2002-03 LEND occupational therapy trainee, was invaluable in assisting with the formal literature review to establish the research base documenting the significant physical and psychological benefits to people through sufficient opportunities for active engagement in meaningful and appropriately challenging activities, opportunities for choice, and group-based horticultural activities. Ms. Porter also contributed significant efforts into the initial development of the *Living with Nature* activity curriculum book and related research and project participation materials and data forms.

The current 2003-04 LEND occupational therapy trainee, **Stacy Springer, BS, OTS**, has been involved in the challenges of the initial implementation of the project, which have been magnified by its being introduced at a brand new residential facility. This combination of factors has been the catalyst for leadership opportunities in the areas of organization, coordination, problem solving, and flexibility with community partners, staff and residents. Ms. Springer is practicing the effective leadership skills that are crucial to the administration of the project, as well as consulting with and supporting the staff to ensure ongoing implementation and success. She is involved in collaborating with interagency professionals at Spring Glen, RSI, NCBG and CDL, as well as gaining experiences in conducting resident participation interest interviews and making necessary program adjustments. Data collection is in progress for resident participation in each *Living With Nature* activity. Along with participation data research activities, Ms. Springer is involved with developing activity analyses of the activities in the *Living With Nature* curriculum.

Future activities planned will include a research study to document the efficacy of the program in enhancing targeted health factors. LEND trainees will continue to be invited to actively participate in leadership activities related to program implementation, research data analysis, and project refinement, with the long term goal of the *Living With Nature* project being to serve as a replicable service model for other professionals working with older adults living in similar residential environments.



This project has yielded a myriad of leadership opportunities...

LEND Program Highlights

HealthSpark

*Daniel Armstrong, PhD
Florida LEND*

The Mailman Center for Child Development has started a project that involves conducting surveys about child health and health care access in two underserved communities in Miami-Dade County. “HealthSpark” is part of a larger collaborative effort, “SPARK,” a county-wide coalition led by the Early Childhood Initiative Foundation and funded through the Kellogg Foundation. The goal of SPARK is to improve school readiness for 1500 three-year-old children enrolled in subsidized child care programs. HealthSpark specifically aims to understand the health needs of this ethnically diverse group of children. What are their greatest health needs? What is the system of health care in their communities? What barriers reduce access to necessary health care? How can we help families get access to health care? How can we support pediatric primary care providers in their efforts to create a medical home? What is the relationship of health and health care to school readiness? In addition to these primary questions, we also hope to answer a number of focused research questions about obesity, neurodevelopment, behavior, and safety in this vulnerable population. HealthSpark is funded by local philanthropic foundations—Health Foundation of South Florida, through Florida’s Ounce of Prevention Fund. This project will evolve into an intervention study in underserved/unserved areas that will support the expansion of existing pediatric health care programs into comprehensive medical homes for children at risk or with special health care needs.



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“Moving On” Transition Program

information is transferred to the adult care team through a medical summary form. The form includes a section where patients and families can share information that is specific to them regarding effective ways to work together as a team. As a final tool for young adults, we have included a flyer with photos and biographical descriptions of each of the adult care team members and their areas of interest and role on the team.

In developing this program, we recognized that many different people needed to be involved to make this a success. We collaborated with patients, parents, adults and pediatric team members who represented an interdisciplinary perspective. We included as many people as possible to ensure ownership and commitment as the program was launched.

By introducing this program at an early age and continuing to build on each stage, we hope to create a safe and smooth transition for the patients and their families. Thus far, we have only utilized this program on young adults on the cusp of transition. It has become increasingly clear that our transition program has provided direction to both patients and staff regarding an individual’s readiness to transition. It has also identified opportunities to provide education and intervention to enhance independence. As with any longitudinal program of this magnitude, the impact will not be fully realized until we have had the opportunity to work with a family through all six stages of transition.

Resources Available

Online Databases of Community-Based Transition Programs for Students

The Transition Coalition at the University of Kansas has created two searchable databases. The *18-21 Programs: Community-Based Special Education Programs* database contains descriptions of over 100 community-based transition programs throughout the United States. The *Transition Grants: OSEP-funded Projects Related to Secondary Special Education and Transition* database contains information regarding transition-related projects administered by the U.S. Department of Education, Office of Special Education Programs.

Visit <http://www.transitioncoalition.org/>, and select either '18-21 Programs' or 'Transition Grants'.

Diagnosis & Management of Pediatric Movement Disorders Online Curriculum

Learn about the **Diagnosis and Management of Pediatric Movement Disorders** via online, interactive case studies! If you treat pediatric patients with spasticity, dystonia, tremor or other movement disorders, these case studies will make you better equipped to enable your patients to live their lives to the fullest.

The Diagnosis and Management of Pediatric Movement Disorders is WE MOVE's latest educational offering for healthcare professionals who treat children and young adults. This course is unique in that it presents a challenging blend of background text and case studies. Interactive cases and accompanying videos challenge participants to refine their diagnostic skills and consider appropriate treatment options. This course will assist clinicians in the diagnosis, management and selection of treatment options for pediatric patients with spasticity, dystonia, tremor, choreoathetosis and other movement disorders.

This educational activity is funded by an educational grant from Medtronic, Inc. Find out more at WE MOVE's Movement Disorder Virtual University at www.mdvu.org.

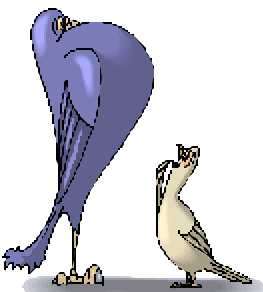
New Bullying Curriculum Addresses Disabilities

Courtney came home from school crying—again. A quiet girl with a beautiful smile and a slight lisp, she hears taunts from the "popular" girls. Karl has cerebral palsy. In silence, he nurses bruises inflicted by a classmate. Karl is afraid to tell anyone because his tormentor threatens harsher treatment if he does.

PACER Center's new innovative curriculum, *"Is Your Child a Target of Bullying? Intervention Strategies for Parents of Children with Disabilities,"* addresses these and other types of bullying. The curriculum is meant for professionals and parent leaders to present to parents at meetings, workshops, and myriad other occasions. Using research-based practices, PACER developed curriculum that offers common-sense information and encouragement to families whose children experience bullying. The curriculum's appealing design and easy-to-follow format attracts and holds attention while delivering important, useable information. The content:

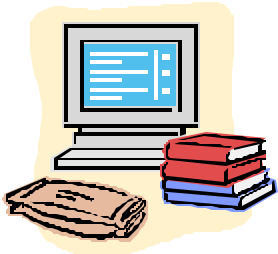
- defines disability harassment and bullying,
- advises parents on how to talk with their child about bullying,
- teaches constructive ways a target can react to bullying,
- educates parents about laws and policies affecting bullying, and
- explains to them how to address bullying in individualized education programs (IEPs).

The curriculum is available from PACER for \$15 in CD-ROM format or \$165 with overhead transparencies and printed script. To order, contact PACER at (888)248-0822 or visit www.pacer.org.



Resources Available

Online Continuing Education Courses in the Field of Disabilities



The University of Miami Mailman Center for Child Development has developed three interactive online courses designed to enhance the skills necessary to provide interdisciplinary, family-centered, and culturally competent services to individuals with disabilities and their families. Developed by a 12-member interdisciplinary faculty curriculum committee, the course materials are presented within the context of interactive family scenarios using current philosophical approaches for working with children, adolescents and adults with developmental disabilities. This interactive case-based approach allows the participant to immediately see the relevancy of the content to their everyday work challenges. All courses are designed to meet the learning needs of a wide scope of professionals in the field of disabilities.

[Interdisciplinary Teaming](#) — *[Family-Centered Care](#)* — *[Self-Determination](#)*

For more information on these courses or to enroll, please see the course website at: <http://pediatrics.med.miami.edu/mailman/homepage.htm>, or contact Paula Lalinde, University of Miami School of Medicine, Department of Pediatrics; plalinde@peds.med.miami.edu; (305) 243-6123.

WWW.MCHCOM.COM

FREE recent and upcoming online events of interest to the MCH community!

- *AMCHP Conference* archived transcripts and slices (March, 2004)
- *MCH Needs Assessment and State Performance Measures Technical Assistance Workshop*
- *MCH Epidemiology Conference* slices and transcripts (December, 2003)
- *2004 MCH Working Conference: The Future of MCH Leadership Training* (April, 2004)

Thousands of ADA Documents Online: ADA Document Portal

More than 3,400 ADA documents are on-line! Developed by a sister agency in Colorado Springs with funding from the National Institute on Disability and Rehabilitation Research, the ADA Portal includes regulations, technical assistance manuals, settlement agreements, and opinion letters. The new ADA Portal also offers documents on other disability rights laws like the Air Carriers Access Act. <http://www.adaportal.org/>

Public Health Infrastructure

The Public Health Foundation (PHF) announces its new website: <http://www.ohf.org/infrastructure>. This searchable site is a gateway to information about the infrastructure of public health systems that protect the public's health. The Public Health Infrastructure Resource Center (PHIRC) provides those wanting to strengthen public health systems with information on the three core areas of infrastructure (as defined by the CDC): (1) The public health workforce, (2) Information, data, and communication systems, and (3) Organizational and systems capacity.

Resources Available

Futures Planning for Families

A new resource on futures planning for families has recently been published by The Arc of the United States and the Rehabilitation Research and Training Center on Aging with Intellectual and Developmental Disabilities, Department of Disability and Human Development, College of Applied Health Sciences University, University of Illinois at Chicago. A *Family Handbook on Future Planning* is a guide to help families develop a future plan for their sons or daughters with cognitive, intellectual or developmental disabilities that provides personal, financial and legal protections for these individuals after the parents either die or can no longer provide care or support. The handbook is available online at:

<http://www.thearc.org/publications/futureplanninghandbook.doc>.

Boston LEAH Web Initiatives

The Boston LEAH Program has a number of new initiatives including updating our website www.bostonleah.org. We have included a number of transition tools developed during a HRTW project for families, youth, and providers, which can be found at <http://www.bostonleah.org/transitions.html>. You can also find new materials on our Center for Young Women's Health website (www.youngwomenshealth.org) about dating violence prevention for 12-15 year old girls (teen materials and curriculum, developed under a contract from the Office of Women's Health) as well as nutrition and fitness materials.



LENDlinks Title V Training Consortium

One of the greatest needs for continuing education exists at the community level in rural, underserved areas. LENDlinks has helped to bridge that knowledge gap by developing and disseminating videoconferences and distance learning modules targeted for state Title V personnel and related agencies in HHS Regions V and VIII to improve systems of care for CSHCN with mental health problems. The Indiana LEND, Riley Child Development Center at Riley Hospital in Indianapolis, IN, is in the second year of an MCHB Continuing Education/Distance Learning Project entitled "*LENDlinks: A Title V Training Consortium For Creating Distance Learning Modules On Bright Futures in Practice: Mental Health Issues in Infants and Children (birth-age 6)*." Four videoconference programs have been held to date and are archived for video stream download/replay at the project website www.LENDlinks.net. A brief description of each program is also available on this website.

Session 1 - "Introduction to Bright Futures Infant Mental Health: The First Year"

Session 2 - "Introduction to Bright Futures Infant Mental Health: The First Year
Assessment Tools"

Session 3 - "Violence and Young Children: What Parents and Providers Can Do To Help"

Session 4 - "Kicked Out of Preschool: Disruptive Behavior Disorders in Early Childhood"

For more information contact Lann E. Thompson, Ed.D., MSSW, MA, LENDlinks Project Coord., Assoc. Dir./Assoc. Faculty, Riley Child Development Center: lann@child-dev.com (317-274-9762).

Employment Opportunities

Pre-Doctoral Fellowship

Children & Developmental Disabilities

Supported by a Training Grant from MCHB, HRSA

The University of Missouri-Columbia School of Social Work, in collaboration with the MCH LEND Program, announces a Fellowship for an entering doctoral student in Social Work for the 2004-2005 academic year*. **\$11,000-\$15,000* plus tuition waiver** (*depending upon qualifications of the applicant and renewal of the grant)

Consistent with our mission to provide training for research to inform policy and practice for social and economic justice, *applicants for this fellowship should possess an MSW and be interested in policy/practice research for children with neurodevelopmental disabilities.*

For more information, please contact:

Marjorie Sable, DrPH, MSW; Director of Doctoral Studies, School of Social Work; University of Missouri-Columbia; 726 Clark Hall; Columbia, MO 65211-4470; (573) 882-0914; SableM@missouri.edu.

The University of Missouri-Columbia is an Equal Opportunity Affirmative Action Employer
Website: <http://ssw.missouri.edu>.



Coordinator of Research and Evaluation

Institute on Disabilities, College of Education, Temple University

Duties: The Coordinator of Research and Evaluation will be responsible for developing and implementing a variety of research and evaluation activities for the Institute on Disabilities and its programs. Responsibilities include (1) developing an annual evaluation of the Institute's accomplishments and outcomes; (2) ensuring that all projects have an IRB-approved and effective evaluation plan measuring consumer satisfaction and outcomes; (3) establishing an annual research agenda and encouraging research initiatives of all faculty, staff, and students; (4) ensuring that all research (both quantitative and qualitative) conducted by staff and students is constituency-oriented; (5) (co-) teaching a course in Constituency-Oriented Research and Dissemination; (6) securing funding through grants and contracts to sustain and expand the research and evaluation activities of the Institute on Disabilities; and (7) participation in the conduct of actual research and evaluation of programs of the Institute on Disabilities. Finally, the Coordinator of Research and Evaluation, who will report directly to the Executive Director, will supervise staff and students within the core area of research and evaluation and will be a member of the Institute on Disabilities' management committee.

Qualifications: (1) Master's Degree in a human service or behavioral science field with an emphasis on applied research and evaluation; doctorate preferred; (2) knowledge of the field of disabilities, especially federal, state and local policies and services concerning people with disabilities; (3) active research (both qualitative and quantitative), publishing, and grant development in disabilities; and (4) ability to work collaboratively as part of a team and with other agencies. Statewide travel is required. Experience teaching in Disability Studies is preferred.

The Institute on Disabilities at Temple University is an equal opportunity employer and encourages applications from qualified minorities and persons with disabilities.

We offer an excellent salary and benefits program including 100% prepaid tuition up to 6 credits/semester. Interested applicants should contact Dr. Diane Nelson Bryen, Executive Director, Institute on Disabilities, Ritter Annex 440, Temple University, Philadelphia, PA 19122; (215) 204-1356 (voice & TTY); (215) 204-6336 (fax); e-mail: dianeb@temple.edu. Visit our Web Site at <http://disabilities.temple.edu>.

All employment opportunities can be viewed at

http://www.aucd.org/aucd_employment.htm

Upcoming Events

MCHB Title V All-Grantees Meeting

October 3-6, 2004
Hyatt Regency, Crystal City, VA

*"The Power of Partnership:
Meeting Today's MCH Challenges
Through Partnerships"*

Beyond Assessment: The Team Approach to Nutrition and Feeding Interventions for Children with Special Needs

When: May 16-18, 2004

Where: Radisson Hotel, Los Angeles, CA

Contact: www.uscuap.org (blue CHILD Center tab, scroll to Events); or (323) 671-3834.



17th Annual MCH Leadership Conference: Making Change Happen—Translating Research into MCH Public Health Practice: The Role of Evaluation

When: May 17-18, 2004

Where: Hilton Garden Inn, Chicago, IL

Contact: www.uic.edu/sph/mch/ce/mch_leadership

Can't make it to Chicago?

Attend the Leadership Conference LIVE and completely ONLINE at www.uic.edu/sph/mch/ce/mch_leadership/.

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MCH Collaborative Network at UAB

formalizing the existing network and increasing opportunities and knowledge for both faculty and trainees. Each training program is represented on a Steering Committee, which meets monthly.

The mission statement of the UAB MCH Collaborative Network is "to establish a partnership that enhances the partners' ability to provide interdisciplinary MCH leadership training, continuing education, and child, youth, and family advocacy to graduate students, trainees, Title V partners, MCH providers, and faculty within Alabama, the region, and beyond."

UAB MCH Collaborative Network activities to date include:

- Ongoing distribution of a combined monthly training calendar
- Establishment of a web page: www.soph.uab.edu/mchb-itp
- Joint viewing of MCH web casts
- Shared faculty
- Joint presentations by faculty to encourage increased awareness and understanding of UAB's MCHB-funded interdisciplinary training programs and related training experiences
- Student-planned MCH Seminars, with student representatives from each training project
- A subcommittee is exploring the possibility of providing a continuing education activity on transition of health care for CSHCN
- Faculty members from each training project are also actively participating in the State of Alabama's Healthy People 2010 Workgroups

Formalizing the collaborative network has been very positive for the MCHB-supported training projects at UAB. The UAB MCH Collaborative Network continues to capitalize on UAB's unique situation of having four MCHB-funded long-term interdisciplinary training projects on campus. Future possibilities for the network include providing a continuing education activity on transition of CSHCN, enhancing and continuing to support state activities with consumers and other state MCH and community partners and addressing regional issues and concerns.

Trainee Corner

Trainee Linkages: Oregon LEND Experience

*Amy Hally, MS, Oregon LEND
Dan Davis, Ph.D, Iowa LEND & AUCD Virtual Trainee
Peter A. Blasco, MD, Oregon LEND*

LEND Directors have focused increasing attention on the need to get LEND trainees connected to the national training network and, more importantly, establish relationships throughout this expansive network to maximize learning experiences. At the 2003 AUCD Annual Meeting a number of LEND trainees participated in a workgroup on increasing trainee linkages. In this workgroup, trainees expressed interest in learning how different programs in the network implement LEND training and in visiting other LEND programs as an avenue to nurture relationships throughout the network.

For several years, Oregon LEND has made a concerted effort to exchange trainees with other LEND programs. The trainees always rave about the value of the “new/different” perspective it offers them. The following detailed description of the most recent experience comes from the perspective of the trainees involved.

In February 2004, **Amy Hally, MS**, a Speech/Language Pathology trainee from the Oregon LEND program at the Oregon Institute on Disability and Development (OIDD), contacted **Daniel Davis, PhD**, Psychology Fellow, at the Iowa LEND at The University of Iowa's Center for Disabilities and Development (CDD), to arrange a visit. In response to Amy's request, **Suzanne Pearson**, Iowa LEND Training Director at the CDD, set up a schedule of clinical experiences, visits with professionals in Amy's specialty area, and dialogue with Iowa's LEND trainees. The visit allowed Amy to experience both training at the Iowa LEND and networking and information exchange among LEND trainees.

Amy visited multiple sites within the University of Iowa Hospital setting and met with LEND trainees and training coordinators. She observed evaluations at the Otolaryngology Clinic at the University of Iowa Hospitals and Clinics and evaluations at the CDD. The speech-language pathologist shared information regarding their clinic operation and information about their clientele. She toured their facility and met the clinical director at the Wendell Johnson Hearing and Speech Center. In addition, Amy also met with **Richard Hurtig**, director of the Speech and Hearing Sciences Program, visited his augmentative and alternative communication lab, and received information regarding his latest projects.

Two projects were of particular interest to Amy. In the Iowa LEND's *Families as Mentors* project, the trainee follows a family through a daylong evaluation at the CDD. Then the trainee is required to meet with the family in community settings approximately once per month to learn what happens over time after the evaluation. For another project, Iowa LEND trainees identify one element within their current care system that could be improved. Following the identification of specific areas of concern, they brainstorm ideas for change with their supervisors. This creates an open line of communication between trainees and supervisors for matters of improvement within the system, acknowledging and taking advantage of students' fresh perspectives.

This exchange also enriched the training of Iowa LEND trainees by allowing them a greater understanding of the interdisciplinary and leadership training of another LEND program and established relationships among trainees across the network. Informal discussion over pizza among Iowa LEND trainees, LEND supervisors, and Amy was arranged. Specifically the trainees and training coordinators inquired about Oregon's methods for completion of leadership requirements. They asked about the types of clinics offered and the number of clients seen per day. They also asked about the Interdisciplinary Forum and topics presented.

The visit was deemed a “wonderful success” on both ends. The Oregon LEND faculty greatly appreciates the effort of the Iowa LEND program on Amy's behalf, and we extend an open invitation to anyone who would like to visit our LEND program. There is much to offer between trainees and LEND supervisors between programs. Oregon and Washington LEND Nutrition trainees have participated in similar exchange programs this past year. It is our hope that other LEND Trainees can benefit from broadening their training and their connections to the network through similar exchanges. Faculty exchanges (i.e., Visiting Professor-type arrangements) could be considered as well.

There is much to offer between trainees and LEND supervisors between programs.

Trainee Corner

Virtual Trainee Update

Dan Davis, Psychology Fellow, Iowa LEND & AUCD Virtual Trainee

Producing leaders and leadership training are defining aspects of LEND programs. I've always felt that one aspect of leadership was advocacy, and in the last two months, I have had the opportunity to participate in the annual meeting of the Association of Maternal and Child Health Programs (AMCHP) and the jointly sponsored Governmental Affairs Seminar. As a trainee, the AMCHP conference provided me with valuable learning experiences in not only in how the Title V Maternal and Child Health Block Grant improves health services to women, children, and families, but also the importance of the grant directly funding the LEND training I receive, and role of LENDs within a network of other health care programs. Moreover, I gained direct experience in working with other groups and lobbyists to advocate for individuals with special health care needs, disabilities, and their families. What was particularly meaningful for me was the feedback I received from the legislative staff of my state Senators regarding the importance of my presence and role as a LEND trainee who directly benefits from the Title V Block Grant, and further provides services that benefit their constituents.

The jointly sponsored Governmental Affairs Seminar was also a valuable learning and leadership experience, and one that was shared by a record number of LEND trainees. Again, it was an opportunity for legislative advocacy at the federal level. Training sessions also provided education in the history, legislative action, funding, and outlook of current legislation and policy including the Individuals with Disabilities Education Act, the Americans with Disabilities Act, Assistive Technology Act, Social Security Protection Act, Workforce Investment Act, Transportation Equity Act, and grants for housing.

As a trainee, what I found most useful and informative from both of these experiences was learning not only why these specific pieces of policy are important for individuals with special health care needs and persons with disabilities, but also the importance of taking an active role as a leader in the development of policy and the legislative process. While it was fascinating to learn how sometimes subtle nuances can profoundly impact legislation, it was more meaningful to experience the role of being an advocate who educates and impacts policy makers not only as a citizen, but also a professional. The skills I learned in how to effectively advocate by being knowledgeable and willing to educate, making issues meaningful, and building relationships will be useful immediately and throughout my professional career. I strongly encourage LEND trainees to avail themselves of opportunities to become involved in leadership activities that involve policy and legislation as they become available in the future.

Be sure to check the trainee website for message board news, virtual trainee updates, events, and more!

You can find the website at www.aucd.org/aucd_trainees.

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

Interested candidates should forward a resume and brief letter of interest to Crystal Clement (cclement@aucd.org) by **June 30**. Please contact either Crystal or current trainee Dan Davis (davisdp@mail.medicine.uiowa.edu) with questions.

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

View the position description and requirements at http://www.aucd.org/aucd_trainees.htm.



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

This newsletter is supported in part by MCHB.
Editor: Crystal Clement, AUCD Project Specialist.

For future submissions and comments, please contact
Crystal Clement at
cclement@aucd.org or 301-588-8252.

AUCD Annual Meeting: Call for Participation!

The 2004 AUCD Annual Meeting and Conference will provide an opportunity to celebrate our partners and to explore how partnerships, networks and other formal and informal collaborations can help realize the vision of full participation of persons with disabilities and their families in the life of our communities and nation.

The themes of partnership across many dimensions, full participation and systems change will pervade the conference. You will have an opportunity to explore the AUCD network's collaborative efforts in leadership; new and exemplary partnerships at the local state and national levels; policymaking initiatives; supports and services to families and individuals; training and technical assistance as instruments of systems change; and newer approaches to full participation such as universal design. You will hear from our federal agency partners, including details about new program initiatives and funding opportunities. You will also learn from other partners, traditional and new, in formal presentations, informal discussions and networking. We invite you to be a partner in this important Annual Meeting and Conference by responding to this Call for Participation and by being part of our Conference agenda.

Visit http://www.aucd.org/AnnMtg/2004_main_page.htm to view a complete description of the 2004 Annual Meeting and Conference, as well as access:

- A Call for Participation flyer for posting at your location
- Proposal Submission Guidelines (**Proposals due via web form: June 21, 2004**)
- Presentation Format Descriptions and Accessibility Guidelines

We look forward to seeing you in November!

2004 AUCD Annual Meeting and
Conference

***Building Partnerships for Full
Participation:
Systems Change Through
Research, Education and Service***

November 7-10, 2004
Hyatt Regency, Bethesda,
Maryland