



News from AUCD

“Every now and then go away, even briefly, have a little relaxation, for when you come back to your work your judgment will be surer; since to remain constantly at work will cause you to lose power”

—Leonardo Da Vinci

Hopefully summer was a time of rest and rejuvenation for all, whether it was a month-long vacation with family or a lazy Labor Day weekend in the yard. We welcome you back to the start of a new school year and trust this finds you full of inspiration and excitement to both learn and serve.

As both faculty and trainees begin to settle in, we would like to update you on what has happened at AUCD over the summer months.

- Half of the 35 LEND programs participated in the funding competition this year, and we are excited to welcome a new program to our network. Located in Washington, DC, the Children’s National Medical Center (CNMC) LEND collaborates with Georgetown University, The Catholic University of America and Howard University and is led by Dr. Mark Batshaw. Please see the article on page two of this newsletter to learn more about CNMC’s exciting program.
- The National Training Directors Council has been busy creating new ways for trainees to connect across the nation. You may have seen listserv messages about the new Distance Mentoring option available to trainees. If you haven’t, be sure to check out either the Trainees or Training Directors Council webpages of www.aucd.org.
- With the new school year comes a new Virtual Trainee, and we are excited to be working with Ann Cameron Williams from the University of Illinois-Chicago UCEDD. “Meet” Ann Cameron on page seven.
- Our office has been busy putting together plans for AUCD’s 2004 Annual Meeting & Conference and is looking forward to seeing both old and new friends. Entitled *Building Partnerships for Full Participation: Systems Change Through Research,*

Education and Service, the conference will take place November 7-10 in Bethesda, MD. See the announcement on page eight of this newsletter for information, including trainee stipends and registration.

We hope you find this issue of LEND Links useful and informative. All the staff at AUCD Central Office look forward to working with LEND staff, faculty and trainees in the coming year! 🌟

*Remember, the next LEND Links will be distributed in February. Please send your submissions to Crystal Clement (cclement@aucd.org) by **January 14, 2005.***

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LEND Program Highlights

A New LEND Program in Washington, D. C.

Gaetano R. Lotrecchiano
Children's National Medical Center LEND




The Children's National Medical Center (CNMC) successfully competed in 2004 to develop a new LEND program that includes collaborations with Georgetown, The Catholic University of America and Howard University. CNMC has a rich academic environment that spans the dimensions of patient care, research and education in neurodevelopmental disabilities. Founded in 1870, CNMC is one of the nation's oldest independent children's hospitals and is the only children's hospital in the Washington, D.C. metro area and serves a population of over 5 million. CNMC is rated among the top 10 Children's Hospitals by both *US News and World Reports* and *Child* magazines. It includes a 220-bed hospital, 5 community-based health centers within the District of Columbia, 6 regional outpatient facilities in Maryland, Virginia and Northwest D.C., as well as the Children's Research Institute (CRI), which is located within the Children's Hospital building. CNMC has over 300 faculty members and 3,000 staff, including among faculty members 52% women and 15% members of under-represented minorities. Faculty hold full-time appointments at the George Washington University School of Medicine and Health Sciences (GW), where CNMC serves as its Department of Pediatrics. CNMC faculty teach both clinical and pre-clinical courses at GW and all GW medical students come to CNMC for their clinical clerkship in pediatrics. There are 180 graduate medical education trainees (residents and fellows); more than half are women and 20% are from under-represented minorities. Over 100 trainees from all of the LEND disciplines have clinical rotations through CNMC.

The Director of the CNMC LEND program is Mark L. Batshaw, MD, a neurodevelopmental pediatrician, who was a former LEND trainee at the Kennedy Krieger Institute and former founding director of the LEND program at Children's Seashore House/Children's Hospital of Philadelphia. He is currently the Chief Academic Officer at CNMC and Chairman of Pediatrics and Associate Dean for Academic Affairs at George Washington University School of Medicine. The Co-Program Directors are John Parrish, PhD, a clinical psychologist who, like Dr. Batshaw, was a LEND trainee at Kennedy Krieger and played a major role in the LEND program at Children's Seashore House and Toby Long, PhD, a physical therapist who was a trainee and former director of the Georgetown University LEND program. The CNMC LEND welcomed its first class of 20 trainees from 8 disciplines in September. We also submitted a proposal to the ACGME to establish a residency in neurodevelopmental disabilities and plan to accept our first trainee in the discipline in July, 2005. We are excited about joining the LEND family and look forward to forming close bonds with our neighboring LEND programs in Maryland and Virginia. 🌐

VT-ILEHP Staff Publishes Book

Stephen Contompasis, MD
Vermont LEND



Caring For Children with Neurodevelopmental Disabilities and their Families: An Innovative Approach to Interdisciplinary Practice is edited by Claudia Vargas and Patricia Prelock, with interdisciplinary collaboration from all Vermont ILEHP interdisciplinary faculty.

This book presents a model multidisciplinary approach to care, family centered and collaborative, that has proven effective in practice. A pillar of the approach is recognition of the importance of performing culturally competent assessments and adjusting service delivery so that it is responsive to cultural differences. Detailed case stories illuminate the ways in which the approach can help children with different backgrounds and different disabilities. Most chapters include, besides references, study questions, lists of resources, and glossaries to facilitate easy comprehension by professionals with many different backgrounds as well as students, trainees and educated parents.

Books are available for \$45.00 and \$99.95 at www.erlbaum.com. 🌐

LEND Program Highlights

Students Present Community Agency Projects & Research

Carolyn H. Richardson, EdD
New Mexico LEND

Two projects in the leadership curriculum of the NM LEND program enable students to gain experience in presenting their work. For the first project, each student interviews a community program that serves individuals with disabilities or special health care needs and/or their families about agency operations. Agencies represented have ranged from a housing option for families with a member undergoing treatment for cancer to a charter school providing full inclusion for children with disabilities and their typically developing peers. Each student then develops a poster, invites a representative from the agency and presents the poster to both students and faculty for feedback and to Center for Development and Disability staff, Health Sciences Center staff and invited guests.

The second opportunity for practicing presentation skills begins at the beginning of the year when each student selects a research project that will increase their skills in scholarly research. Each student works throughout the year to complete her/his project and develop a 15-minute formal presentation incorporating visuals, handouts and an audio enhancement system. Samples of the projects presented last year include: *Meal Time Study of Children with Autism*, a pilot study of *Facilitating Job Retention for Direct Support Professionals: Exploring Effective Statewide and National Interventions*, and *The Development of a Best Practice Action Plan for Children with Autism Spectrum Disorder in New Mexico*. The results of this last project were included in a state policy brief.



Faculty mentors encourage students to present their research as a poster during the annual Southwest Conference on Disability. During this statewide conference one student is selected to receive the Outstanding Student Researcher Award. One of the NM-LEND students from this past year has been nominated to receive this award in October 2004. 🌟

LEND Research Project Poster Session

Karen Edwards, MD
Westchester LEND

The annual Westchester Institute for Human Development *LEND Research Project Poster Session* was held on May 2, 2004. Each LEND research team presented the results of their yearlong project and answered questions from the medical college community about their research. The poster session is the culmination of the WIHD LEND research curriculum. Trainees participate in research seminars and work in 2- to 4-person faculty supervised research teams to fulfill the curriculum requirements. Research seminars address research ethics, methodology and analysis as well as identifying funding sources, applying for a grant and giving an effective presentation.

This year's studies included an investigation of factors affecting dietary adherence in children with inherited metabolic disorders, a survey of family and health professional preferences as part of a needs assessment for development of a new Family Resource Center at the Children's Hospital at Westchester Medical Center, a study of prevalence of autism spectrum disorders as determined through EI charts, a determination of predictors of outcome among families with mandated preventive services and an investigation of the occurrence of post-traumatic stress in children in foster care.

Trainees receive feedback concerning their research from poster session participants and in the form of a written evaluation by their team leaders and the director of research for LEND. 🌟

Upcoming Events

Continuing Education Videoconferences coordinated by JFK Partners and delivered in part by JFK Partners, UCHSC, the MCH Section in the State of Colorado Department of Public Health & Environment and the LENDlinks project at the Riley Child Development Center in Indianapolis, IN.

- Prenatal Weight Gain – **October 13, 2004**
- Teen Motor Vehicle Safety – **October 28, 2004**
- Update on Pediatric Sleep Disorders – **December 8, 2004**
- Collaborating with Community Partners – **January 19, 2005**
- Issues in Aging of Persons with Disabilities – **January 26, 2005**
- Obesity Prevention in School-Age and Youth Populations – **February, 2004**
- The Wild Child: Preschoolers who Act Out – **March, 2005**
- Shaken Baby Syndrome – **April, 2005**

Additional information on these exciting interactive videoconferences programs can be found at www.jfkpartners.org or by sending email to rapport.maryjane@tchden.org

January 24-25, 2005: Radisson Hotel, West Los Angeles, California
Beyond Assessment: The Team Approach to Prevention and Intervention for Overweight and Obesity in Children with Developmental Disabilities

The goal of the conference is to promote the health of, and to prevent/treat obesity as a secondary condition in, children with developmental disabilities and/or other special health care needs.

For more information, contact Cary Bujold Kreutzer at (323) 671-3830, or cbujold@chla.usc.edu

February 28 – March 1, 2005: Waikiki, Hawaii

21st Annual Pacific Rim Conference on Disabilities

Topics include international issues, education & employment opportunities, self-determination, health, early childhood and technology.

Visit <http://www.pacrim.hawaii.edu> to learn more about this conference and participate in the Call for Papers and Silent Auction.



May 12-13, 2005: Hyatt Lodge, Oak Brook, Illinois
18th annual UIC MCH Leadership Conference
Translating Research into MCH Public Health Practice

For more information about the upcoming conference please visit the website www.uic.edu/sph/mch/ce_ta or contact Kris Gupta at 312.996.2875 or kygupta@uic.edu
 Hyatt website: www.thelodge.hyatt.com

2005, 2006, 2007: MCHB-sponsored Distance Learning Project

Interdisciplinary Leadership Training in Overweight Prevention and Intervention in Children with Special Health Care Needs

This collaborative continuing education distance-learning project is designed to meet the need for interdisciplinary leadership training in overweight prevention and intervention for CSHCN by providing both an instructional videoconference and a self-paced, web-based, interactive, educational program to be accessible to MCH and Title V programs.

The Boling Center Department of Nutrition, the Strong Center for Developmental Disabilities LEND, the Child Developmental and Rehabilitation Center LEND in Portland, OR and the Department of Nutrition in Knoxville, TN are collaborating on this project.

Resources Available

<p style="text-align: center;">Archived Webcasts: UIC MCH Leadership Conferences</p> <p>2002-2004 UIC MCH Leadership Conferences, <i>Translating Research into MCH Public Health Practice</i>.</p> <p>At the 2004 conference, Dr. Michael Quinn Patton gave an inspiring talk about the importance of making evaluation useful and of creating a positive culture around evaluation. Listen to learn more about learning-driven evaluations and results oriented, reality-testing leadership. http://www.uic.edu/sph/mch/ce/mch_leadership/</p>	<p style="text-align: center;">FY05 HRSA Preview</p> <p>The FY05 HRSA preview has been published! The HRSA Preview is a comprehensive review of HRSA's FY 2005 competitive grant programs. Grant offerings in this single-source include MCHB, Health Professions, Early Hearing Screening, Children with Special Health Care Needs, HIV, Loan Repayments and many others.</p> <p>Detailed information in the form of a 288-page PDF file and individual links can be found at www.hrsa.gov/grants/preview/.</p>
<p style="text-align: center;">Collaborating to End Crimes Against People with Disabilities</p> <p>Research has shown that people with disabilities are at a higher risk for being victims of crime and violence than other groups. Although it is still not clear how extensive the problem is, it is clear that a serious concern exists for the millions of Americans who have disabilities, as well as for those who care for and serve them.</p> <p>WIND's Victims of Crime with Disabilities Resource Guide features extensive information and a variety of search and display options, including an online calendar (searchable by state), a funding opportunities section and message boards.</p> <p>Visit the web site at http://wind.uwyo.edu/resourceguide/.</p>	<p style="text-align: center;">Early Childhood Development in Social Context</p> <p style="text-align: center;">New Report Looks at How Young Children Are Faring on Key Markers of Development</p> <p>The Commonwealth Fund has released <i>Early Child Development in Social Context: A Chartbook</i> in partnership with the American Academy of Pediatrics' Center for Child Health. The 115-page chartbook reviews and explains 33 indicators of intellectual, social, and emotional development for children up to age six and of family and neighborhood characteristics that affect children's readiness for school.</p> <p>View the <i>Chartbook</i> PDF: www.childtrends.org.</p>
<p style="text-align: center;">Health Concerns of American Indians & Alaskan Natives Addressed</p> <p>American Indian Health, a new National Library of Medicine website, presents information on issues affecting the health and well-being of American Indians and Alaska Natives. The website is designed to bring together health and medical resources, including policies, consumer health information and research. Information on traditional healing resources and links to an assortment of documents, websites, databases and other resources is also provided. The website is available at http://americanindianhealth.nlm.nih.gov.</p>	<p style="text-align: center;">Genetic Policy and Law Database by NHGRI</p> <p style="text-align: center;">Free Web-based Resource For Finding Federal & State Laws Related to Genetic Issues</p> <p>The National Human Genome Research Institute (NHGRI) Policy and Legislation Database is located on NHGRI's Web site at http://www.genome.gov/LegislativeDatabase. The free, searchable database currently focuses on the following subject areas: genetic testing and counseling, insurance and employment discrimination, newborn screening, privacy of genetic information and confidentiality, informed consent, and more.</p>
<p style="text-align: center;">Survey Assesses Prevalence and Characteristics of Children with Special Health Care Needs</p> <p>"Although many [children with special health care needs] appear to be receiving the services they need, our findings suggest that children in low-income families, those in selected racial and ethnic minority groups, and those without health insurance experience disproportionate barriers to accessing care, have lower rates of access to care, and are less likely to be satisfied with the services they receive," write the authors of an article published in the September 2004 issue of the <i>Archives of Pediatrics and Adolescent Medicine</i>.</p> <p>van Dyck P, Kogan MD, McPherson MG, et al. (2004). Prevalence and characteristics of children with special health care needs. <i>Archives of Pediatrics and Adolescent Medicine</i> 158(9). http://www.mchlibrary.info/KnowledgePaths/kp_CSHCN.</p>	

Employment Opportunities

Psychology Faculty

Baylor College of Medicine, Texas

The Adolescent Medicine and Sports Medicine Section, Department of Pediatrics, Baylor College of Medicine, is recruiting a full-time, tenure-track psychology faculty member. The psychology faculty will provide clinical service, supervise postdoctoral fellows and develop a special area of research expertise. Education: PhD in Clinical Psychology Experience: At least two years of clinical experience in providing services to adolescents in an interdisciplinary setting; at least one year of experience in supervising psychology graduate students. Licensing: Must be licensed or license-eligible in Texas and be able to obtain licensing by the end of one year. Baylor College of Medicine is an Equal Opportunity Employer.

For additional information contact Albert Hergenroeder, MD at 832-822-3658.

More employment opportunities

can be viewed at

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

AUCD-CDC Project Director

AUCD, Silver Spring, MD

The Project Director will direct, manage and coordinate AUCD's efforts under a federal cooperative agreement with the CDC's National Center for Birth Defects and Developmental Disabilities (NCBDDD) to strengthen the nation's capacity to carry out public health activities in the areas of birth defects, developmental disabilities and health promotion for people living with disabilities. The Project Director works directly with CDC officials, the AUCD network of centers and programs, sub-award grantees, and other partnering organizations that focus on BD/DD and special health care needs. The position offers a highly competitive salary, benefits package and an opportunity to strengthen the entire AUCD network's work in the area of health and disability. For information on desired qualifications and application procedures go to: http://www.aucd.org/projects/NCBDDD/proj_dir_job_desc.htm or http://www.aucd.org/aucd_employment.htm

AUCD Leadership Fellowship in Disability

AUCD, Silver Spring, MD

This position offers significant experience at the AUCD central office in national level activities related to disability policy and legislative development, advocacy, program development, technical assistance, and association administration. This opportunity is for staff working for at least 2-5 years at a UCEDD, LEND program or MRDDRC in a management, faculty, research or clinical position who are US citizens, or for graduate trainees who are completing their training program. Detailed application information is available at:

http://www.aucd.org/employment/PolicyFellow_AUCD.htm

Applications are being accepted for both AUCD positions with a tentative hire date of November for the Director Position and a projected start date of January or February for the Fellowship. Please pass on these national level opportunities to others who may be interested and qualified. Persons from diverse cultures and persons with disabilities are encouraged to apply.

Trainee Corner

Virtual Trainee Update

*Ann Cameron Williams, Chicago UCEDD &
AUCD Virtual Trainee*

Please allow me the pleasure of introducing myself as the new Virtual Trainee for the AUCD. My name is **Ann Cameron Williams**, and I am a doctoral candidate at the University of Illinois at Chicago's Disability Studies Program.

So, what exactly is a "Virtual Trainee?" Borrowing from descriptions penned by Daniel Davis and Beth Bryant (former AUCD Virtual Trainees), I'd like to use and slightly adapt their description of the function of the Virtual Trainee position, which stated: "The nature of the Virtual Trainee position is two-fold: 1) I will 'virtually' work for AUCD while physically remaining a full-time student at the University of Illinois at Chicago in the Disability Studies Program, and 2) I will be reaching out electronically to 'virtually' link trainees across the country with each other and with the AUCD network at large." This is a wonderful opportunity to serve a national network of students, researchers and others interested in disabilities, to learn about AUCD as an organization dedicated to advancement and practice for persons with disabilities and their families at the national level, and to meet other trainees with similar interests and experiences. I am honored to have been selected for this position.

My educational background includes graduate studies at the University of Chicago in Liberal Arts and undergraduate studies at Cornell College in Mount Vernon, Iowa. I was introduced to UIC's Disability Studies Program in 2000 and have been going through the doctoral coursework since then under the advisorship of Dr. Tamar Heller. The Disability Studies Program at UIC has been an incredible program in teaching emerging perspectives of disability in social sciences, cultural and political arenas. My research interests focus on juvenile offenders with disabilities in the juvenile justice system and I am actively working on my dissertation which explores attitudes towards diverse disabilities among staff in this environment. Professionally I have worked in development for non-profit organizations in developmental disability and child welfare fields and am a consultant in programmatic evaluations, designing information systems and RFP/grant development. My interest and proximity to disability stems from my personal experience as a mother of a child with Down syndrome. Geoffrey is 10 and is the greatest of my accomplishments.

My **goal** as the Virtual Trainee for the upcoming year is to learn as much as possible about the AUCD networks in order to raise awareness and increase participation in AUCD activities among the trainee community and to be actively involved as a trainee representative in organizational events and initiatives. Fostering interactive and meaningful communications among trainees in the field is important for so many good reasons and I hope that my energies and abilities to engage others in these communications will serve AUCD members well.

I look forward to meeting many of you over the next year, both "virtually" as well as in person.

Sincerely,

Ann Cameron Williams
AUCD Virtual Trainee
Doctoral Candidate, Disability Studies
The University of Illinois at Chicago
Acw1965@uic.edu



**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](http://www.aucd.org/aucd_trainees)**



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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 LEND Project Coordinator.

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

The MCHB All Grantees Meeting will extend the efforts of HRSA/MCHB to provide national leadership and work in partnership with states, communities, public-private partners and families to strengthen the MCH infrastructure and build knowledge and human resources in order to assure continued improvement in the health, safety and well-being of the MCHB population. The meeting's goal is to bring together key partners of MCHB, including grantees and Federal staff, for building synergy and collaboration as well as developing strategies that maximize the effectiveness of MCHB's efforts to meet the needs of the MCHB population.

Visit www.roomers.org to register, book your hotel and view a meeting agenda.

MCHB All-Grantees Meeting

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

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

www.roomers.org

AUCD Annual Meeting

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

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

www.aucd.org

The 2004 AUCD Annual Meeting 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.

Visit http://www.aucd.org/AnnMtg/2004_main_page.htm to view a complete description of the 2004 Annual Meeting and Conference, register, book your hotel or apply for a trainee stipend.

We look forward to seeing you in November!