

LEND LINKS

News from MCHB

Denise Sofka and Madhavi Reddy, MCHB Project Officers

MCHB Announces Pipeline Program grants: Three LEND Programs Benefit

The purpose of the Maternal and Child Health Pipeline Training Program (MCHPTP) is to promote the development of a culturally diverse and representative health care workforce by recruiting, training, and retaining students from under-represented minorities into maternal and child health professions. The Maternal and Child Health Pipeline Training Program (MCHPTP) recruits financially disadvantaged under-represented undergraduate students enrolled at Minority Serving Institutions. The MCH Pipeline Training Program will educate, mentor, guide and provide enriching experiences to increase students' interests in MCH public health professions (pediatrics, public health, pediatric nutrition, public health social work, pediatric nursing, pediatric dentistry, psychology, health education, pediatric occupational/physical therapy, speech language pathology, etc.).

Three of the four funded programs below described coordination with a LEND program in their application. Full abstracts for each of the funded programs can be found at: <http://www.mchb.hrsa.gov/training/programs.asp?program=22>.

Alabama State University, Project Director: Denise M. Chapman-Winn, Ph.D., dchapman@alasu.edu. The collaborative partnership between ASU and UAB's MCH programs will provide an opportunity to positively impact maternal child health practice in Alabama and throughout the region in multiple ways. The UAB MCH programs (LEAH, LEND, PPC, SOPH MCH) will collaborate with ASU to provide onsite courses, as well as opportunities for clinical and leadership experiences at the UAB campus during the summer terms (using existing UAB summer minority student enhancement programs). Likewise, Alabama State University serves as a rich referral source of African American students, to UAB, who are committed to MCH careers and are well on their way to understanding health disparities and becoming cultural competent.

Howard University, Project Director: Denyce S. Calloway, Ph.D., dcalloway@howard.edu. The Department of Health, Human Performance and Leisure Studies has established direct connections with the State Title V agency, the Association of Maternal and Child Health Programs (AMCHP), the Departments of Sociology and Anthropology within the College of Arts and Sciences, the Division of Allied Health Sciences and Nursing, Howard University Medical School, Howard University Child Development Center, and Howard University Hospital. A major partnership has been established with

The MCH Pipeline Training Program promotes the development of a culturally diverse and representative health care workforce by recruiting, training, and retaining students from under-represented minorities into maternal and child public health professions.

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NETWORK NEWS

Legislative Update: Senate Autism Bill Authorizes Expansion of LEND Programs

Kim Musheno, AUCD Legislative Director

The Senate passed by unanimous consent S. 843 the Combating Autism Act of 2006, a bill with that would authorize significant resources for the expansion of LEND programs, just prior to adjourning for the August recess. Information gained from the AUCD network was instrumental in the development of this bill. AUCD participated in a briefing for senate staff on autism earlier this summer. AUCD Executive Director, George Jesien, included information gained from an informal survey of the network regarding autism in his presentation at the briefing. AUCD then worked with senate staff on the development of the language for the bill.

The bill, if passed, would expand the amount of money authorized for research on autism through the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC). In addition, S. 843 asks the Secretary of Health and Human Services to expand existing interdisciplinary training opportunities and to increase the number of sites able to diagnose individuals with autism or other developmental disabilities. For this purpose the bill specifically requires the Secretary to ensure that the Leadership Education in Neurodevelopmental and Related Disabilities programs are expanded and developed in states that do not have such a program. The Secretary must also develop guidelines for interventions and to disseminate such information. It authorizes \$210 million in funding over 5 years (\$32 million for 2007) for this purpose.

S. 843 specifically requires the Secretary to ensure that the Leadership Education in Neurodevelopmental and Related Disabilities programs are expanded and developed in states that do not have such a program

Even though the Senate has passed the bill, little action has taken place in the House. H.R. 2421 was introduced in May 2005 and no action has taken place on it since that time. The version of the bill that passed the Senate is significantly different than the one that was introduced in the House. More work is ahead if the Autism Bill is to be passed into law. Some of you

may be contacted by AUCD or your congressional office to provide information and local district reactions to the proposed bill. AUCD will be providing information as it becomes available. It will take the work of many to get the bill moving in the House and to keep the positive changes made in the senate bill in the final version. For the complete text of the legislation, committee report and summary, please visit the AUCD Legislative Affairs web page. Call Kim Musheno at AUCD if you have questions or suggestions at 301-588-8252 or kmusheno@aucd.org.

AUCD-ESPA Sponsored Projects

Dan Dalton, ESPA



Easter Seals Project ACTION (ESPA) is a national technical assistance program funded through the U.S. Department of Transportation, Federal Transit Administration. Established by Congress in 1988, ESPA promotes cooperation between the transportation and disability communities and works to increase the availability and use of accessible transportation for people with disabilities of all ages through a variety of training, technical assistance and products. ESPA also supports research opportunities and projects. In 2005 AUCD and ESPA met to discuss ways to increase the involvement of university students in accessible transportation issues.

Out of this new partnership grew a sponsored project program that offers AUCD's UCEDD and LEND trainees the opportunity to conduct research that relates to transportation for people with disabilities. The products of this research are used to contribute solutions to the transportation challenges people with disabilities encounter in their communities.

The following trainees competed and were selected for the initial 2005-2006 program:

- Ms. Lauren Giovingo, a Psychology Intern at the University of North Carolina's Center for Development and Learning, examined the extent to which existing state transportation and disaster preparedness plans address transportation for people with disabilities. Ms. Giovingo is acutely aware of the impacts of a natural disaster as she was one of the millions of residents forced to evacuate from New Orleans during Hurricane Katrina.
- Ms. Anna Long, a Psychology Intern and LEND Trainee at the Oregon Institute on Disability and Development, focused on the unique challenges people with physical disabilities encounter when traveling to and from an airport. She examined barriers to transportation experienced by persons with physical disabilities and strategies they use to overcome these barriers.

On July 27, Ms. Giovingo and Ms. Long presented their findings at a meeting of ESPA's National Steering Committee in Washington, D.C. Their final products will be nationally distributed through the ESPA clearinghouse available at www.projectaction.org. In addition, their projects will be highlighted at ESPA's poster session on October 31st at the AUCD Annual Meeting and Conference.

Both AUCD and ESPA are excited to announce an expanded partnership for the 2006-2007 academic year. ESPA will award up to four trainees with stipend amounts of up to \$3,000 per award. Applications are available on the AUCD Web site and are due October 15. For more information and to apply, visit the Trainee webpage of www.aucd.org.



NETWORK NEWS

Boston-ICI LEND Class of '06

David Helm, PhD

The ICI LEND Class of '06 completed their training in May. During their convocation, each fellow presented a summary of their work in the community, each having aligned with a different community-based organization (CBO). The CBO's included the Latin American Health Institute, Somali Development Center, Rafuah, Starlight Ministries, Massachusetts Alliance for Portuguese Speakers, Asian Task Force Against Domestic Violence, Concilio Hispano, Urban Pride, and Multicultural AIDS Coalition. Each fellow reported on their work in the community agency and many of the agency personnel attended the convocation. Fellows also visited a Title V program during the course of their study to gain a better understanding of the breadth of services offered in Massachusetts within the Title V system and to see first-hand some the challenges these providers encounter on a day-to-day basis.

As we prepare for our new grant cycle we continue to expand the outreach to additional CBO's who are affiliated with ICI's LEND program or other ICI/UCEDD initiatives. Our LEND Diversity Director, Rooshey Hasnain, EdD., when

not working for the LEND program, recently received an award from the Massachusetts Department of Mental Retardation, the Paulette Anjorin Community Service Award—presented by the MA Commissioner for the Department of Mental Retardation—for her work with diverse community organizations, bringing them together to better serve individuals with disabilities and their families. This award was presented in alliance with the DMR Urban Youth Collaborative Program.

A new text entitled *Medical Care for Children & Adults with Developmental Disabilities*, (2nd ed.) published by Paul Brookes Pub. Co (2006), co-edited by Leslie Rubin and Allen Crocker, with contributions from seven or eight LEND faculty and former LEND fellows will be used as a teaching aid in our program in the fall.



ICI LEND Class of '06: (top) Allen Crocker, LEND Director; Cristina Mendoza, Tonya Kellerman, Renald Raphael, Jason Wheeler, Justin DiBiasio, David Helm, Program Coordinator, (bottom) Katerina Roussos, Patty Glidden, Patricia Schram, Brett Golub.

OIDD Trainee Receives AUCD-ESPA Funding

Dean H. Westwood, LEND Training Coordinator and Co-Director, Center on Self-Determination, OIDD UCEDD and LEND

Anna Long is a University of Washington Child Clinical Psychology graduate student and has been in the Oregon Health & Science University (OHSU) OIDD LEND program for her clinical internship in 2005-2006. Anna received her PhD in June 2006 and began a pediatric psychology research fellowship at OHSU in September.

In the fall of 2005 an RFP from ESPA and AUCD was released for competition to LEND and UCEDD trainees throughout the Network. Focusing on transportation related barriers for people with disabilities, the grants funded projects up to \$2000. Working with Dean Westwood, MSW, a LEND Training Coordinator at OIDD, Ms. Long submitted a proposal entitled: *Getting to the Airport On Time: Creation and Evaluation of a Consumer-Driven Quick Reference Tool for People with Physical Disabilities*.

Anna's ESPA project examined the barriers that people with physical disabilities face in getting to and from the airport. This project used focus group data from a larger research project on transportation accessibility through the National Institute on Disability Rehabilitation and Research (NIDRR) funded Rehabilitation Engineering and Research Center (RERC) on Accessible Inter-City Transportation sub-contract to the Center on Self-Determination (CSD) at the OIDD. The final product of Anna's project will be a report of the study and a quick reference guide. This guide will be based on advice for overcoming barriers that was given by people with physical disabilities who travel and will be posted on the ESPA Clearinghouse and AUCD websites.

Said Anna, "The Project ACTION funding made it possible for me to do research in an area that was new for me. It also allowed me to make an additional contribution to an existing research project. I enjoyed the opportunity to use my research skills to create a product that will hopefully be helpful for people with physical disabilities. Going to the steering committee meeting was educational; it was great to see so many people working together with the ultimate goal of increasing transportation accessibility."

The LEND program at OIDD is extremely proud of Anna and her tremendous contribution to the field of research and intervention on transportation barriers for people with physical disabilities. This is yet another example of the quality leadership development that takes place when UCEDDs, LENDs, AUCD and partners like ESPA collaborate to deliver usable products for people with disabilities.

Anna's presentation can be viewed at <http://www.ohsu.edu/oidd/CSD/>, and more information on the AUCD-ESPA partnership can be found at <http://www.aucd.org/trainees/espa.htm>.



Anna Long, PhD

**2006-2007 AUCD-ESPA Sponsored
Project applications are now available!**

**Read the details and apply online at
<http://www.aucd.org/trainees/espa.htm>.**

NETWORK NEWS

PLAA Leadership Assessment Scale

Peggy Owen Sands and the VT-ILEHP Team

Announcing the release of the Professional Leadership Abilities Assessment (PLAA) scale! The PLAA is a self-assessment tool for LEND trainees to examine their level of leadership skills that can be used as a pre- and post-training test. The PLAA has been undergoing revisions with feedback from multiple LEND programs over the past two years, and the authors now feel that the tool is ready to be used by Directors in assessing the leadership skills of their trainees within the LEND network.

The authors of the PLAA hope LEND Directors will find the tool useful in helping to direct trainees' attention to leadership skills as well as a way to measure progress in the development of leadership skills. The leadership skills on the PLAA are not all inclusive, but are a sampling to help the trainees and fellows better understand what different leadership skills look like.

The VT ILEHP team would appreciate receiving feedback from Directors who use the PLAA. A request for impressions and ways in which programs have used the PLAA will be sent to the LEND Directors listserv in August 2007.

Thank you to all who took the time to review the PLAA and provide feedback to VT-ILEHP during the revision process; your input was very helpful and allowed the tool to become more comprehensive and succinct.

Questions about the PLAA should be directed to Peggy Owen Sands at powen@uvm.edu.

Download the four documents that make up the PLAA at:
http://www.aucd.org/aucd_lend.htm (see the item marked
 NEW under LEND publications).

Genetic Counseling Update from VaLEND

Joann Bodurtha, MD, MPH

VaLEND looks forward to sharing the first year of experience with the AUCD grant - Synergy - at the LEND directors meeting this fall. This summer has been particularly busy with the first internship in disabilities and genetic counseling. Teleace Gary, a sophomore at Virginia Union University, and Khristian Harris, a rising sophomore at Virginia State University, completed a diverse interdisciplinary experience. Highlights included meeting with our self-advocate at her workplace, varied experiences in ten LEND disciplines, engagement in genetic counseling sessions, and their capstone presentations. Teleace chose to speak about multicultural recruitment to genetic counseling as well as the role of the faith community in genetic education, and Khristian presented on the genetics of obsessive-compulsive conditions. Both undergraduates were mentored by the genetic counseling students who are participating in the VaLEND program. The experiences helped them clarify their career goals and knowledge of neurodevelopmental disabilities. We miss Teleace and Khristian.



New Employee at VaLEND

Joann Bodurtha, MD, MPH

VaLEND recently hired Shantelle Taylor as a new part-time program assistant. She is a junior, Business major at Virginia Commonwealth University, and a native of Petersburg, Virginia. In addition to holding two jobs, Shantelle has volunteered during the summer at Carver Community Center, located in the Carver Community, downtown Richmond. She plans to enter the Real Estate field with a long-term goal of opening a group home for children. Shantelle sought the position with the Va-LEND program as an opportunity to gain a greater knowledge of the various needs of children and available resources. She has a younger relative with a special health care need. VaLEND and the AUCD network welcome Shantelle.

NETWORK NEWS

MCHB

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two MCHB long-term MCH training programs: the Howard University/NIDCD Center for Leadership in Communications Disorders and the Maternal and Child Health Program at the University of Illinois.

University of California, Los Angeles, Project Director: Alice A. Kuo, PhD, MD, MEd, akuo@mednet.ucla.edu. The Pathways for Students into Health Professions (PSHP) Program is not simply linked to the CFHP, an existing MCH Long-Term Training Program; the activities of the PSHP Program are intertwined with that of the CFHP program. Both share the same Community Advisory Board and faculty, administrative support, facilities and resources, and oversight within the School of Public Health. We believe that this integration with the CFHP program will ensure the success of the PSHP Program and create and develop the undergraduate piece of the pathway for future MCH leaders. We also expect to extend our formal memoranda of understanding between the CFHP, the MCH Nutrition Leadership Training Program and the USC LEND program to include the PSHP. This will optimally leverage each of these uniquely targeted programs.

University of Wisconsin, Milwaukee, Project Director: Kris Pizur-Barnekow, Ph.D., krisb@uwm.edu. The proposed project will link with Partnerships for Healthy Milwaukee, the Center for Urban Population Health, and the Wisconsin MCH LEND Program. These programs will facilitate training that is responsive to underserved children with special health care needs and their families. UW-Milwaukee MCH Pipeline Trainees will interact with leaders who specialize in urban health initiatives and will be mentored by MCH LEND Trainees. UW-Milwaukee MCH Pipeline Trainees will have multiple opportunities to interview and observe leaders in public health and population-based research. In addition, MCH Pipeline Trainees will review community needs assessments and other published reports by Title V agencies in the state of Wisconsin.

Meeting

The Division of Children with Special Health Care Needs (DCSHCN) at MCHB convened a meeting on September 14-15, 2006 to discuss the newly established definition of family-centered care. Participants at the meeting are now trying to determine how the definition can be applied to the maintenance of electronic medical records. DCSHCN also will be meeting with the Commonwealth Fund on October 21-22, 2006 to discuss Bright Futures, children with special health care needs and well child care.

Website Redesign

In other news, on September 1, 2006, The MCH Training Program announced the most recent facelift of its website at <http://www.mchb.hrsa.gov/training>. When you look at the website, you will notice that you will now have the opportunity to submit content and search the website for training related topics. Visitors also will notice that links to Grantee Products and the MCH Training Grantee Network are more visible on the left hand side of the Home page. If you click on the double arrows (>>) next to Grantee Products, you will be directed to a page that divides the products into several categories. Currently, the website houses Grantee Products in the areas of Training Materials and Strategies, Evaluation Materials and Strategies, Guidelines and Case Studies, and Other. If you click on the double arrows (>>) next to MCH Training Grantee Network, you will be directed to a page that provides you with a brief description of the network and a link to the MCH Training Grantee Network website for additional information on the services provided by the Institute for Child Health Policy at the University of Florida (website contractor for the MCH Training Program). Major content areas, e.g. About, Strategic Plan, Funded Projects, Applying for a Grant, Grantee Resources, and MCH Resources remain intact, but they have been moved to the center of the page. If you click on each content area, you will be directed to a page that divides content into several subcategories or you can simply click on a subcategory under a content area to get more information. One area that you may notice as strikingly different is the Funded Projects by Region subcategory under Funded Projects. If you move your mouse over the color-coded regions on the map, you will be able to view the states in each region and you can click on a region to view funded projects. Links to the regions also are available on the right hand side of the page. News, MCH People in the News, and Upcoming Events bulletins are still on the right hand side of the Home page. Visitors can click on the More>>> button next to each of these sections to get a complete listing of all recent postings. If you have comments about the redesigned website, please send them directly through the Contact link on the Home page.



NETWORK NEWS

Children's Hospital of Philadelphia LEND Collaborates with City Maternal & Child Health Program

Megan DiTizio, LEND Program Manager

Symme Trachtenberg, MSW, Director, Community Education

The Children's Hospital of Philadelphia LEND is pleased to announce a partnership with the HIP (Health Intervention Program). HIP is a Title V funded home visiting program that focuses on families of children with special health care needs. HIP is coordinated by the City of Philadelphia's Department of Public Health, which contracts with three community agencies to provide services. This free program assists families by creating personal care plans that include parent education, insurance enrollment, and child care services.

LEND faculty and fellows will provide assistance to HIP staff and participating families in the following areas: Cultural Effectiveness, Family-Centered Care, Symptoms, Resources and Treatment options for DD, and Policy and Advocacy.

Cincinnati, Ohio, LEND Program Welcomes Family Trainee

Sheryl Feuer, Parent Coordinator

The LEND program at Cincinnati Children's Hospital Medical Center's Division of Developmental and Behavioral Pediatrics will welcome its first trainee in Family Discipline this fall. The newly established stipend will allow a family member of a child with DD to train alongside students from other disciplines. The Family Discipline trainee will complete the same rigorous requirements as the other LEND trainees, with adaptations to the competencies to reflect the unique nature of the discipline. Not only will the trainee in Family Discipline gain important leadership and advocacy skills, he/she will provide the other trainees with the invaluable perspective of a family member.

"We felt that the establishment of a stipend for a family member was the natural next step in our continuing effort to include families in all aspects of our program," explains training program Director Roz Parrish. Two years ago, the Cincinnati LEND added a family mentoring component, which has received rave reviews from both the participating families and the trainees.

Interest in the new stipend has been encouraging. Says Parrish, "We've received enthusiastic responses from several parents who are eager to further their advocacy skills by broadening their understanding of the issues involved in developmental disabilities as well as the importance of interdisciplinary training."

For more information about the Family Discipline stipend, contact Parent Coordinator Sheryl Feuer at sheryl.feuer@cchmc.org.

AUCD is redesigning our website!
The new and improved site will be released during
AUCD's Annual Meeting and Conference, October 29-November 1, 2006.
Watch for new features, including photos of network members,
program spotlights, and better navigation.

NETWORK NEWS

Oklahoma LEND Long-Term Trainee in Parent-Family Issues becomes new "Family Mentorship Coordinator"

Jan Moss, Oklahoma LEND Core Faculty

"When students see families beyond a patient role, when they learn from and listen to families, when families and professional faculty are observed working together; the partnership is modeled and inspired in ways that no textbook or lecture can describe...One of the most effective ways to introduce the idea of families as partners is to take students to families and to community programs."

--Polly Arango, Pediatric Pulmonary Centers Conference, Washington, DC, March 3, 2006

Crissy Stokes, the second Oklahoma LEND Long-Term Trainee in Parent-Family Issues (2005/2006) will become the new Oklahoma LEND Family Mentorship Coordinator.

Jan Moss, Core Family Faculty for Oklahoma LEND will be mentoring Crissy as they implement the new Family Mentorship Coordinator position utilizing a draft of the "Guidebook for Promising Practices in Family Mentorship" developed by the AUCD MCH-LEND Family Faculty Workgroup over the last year and of which Jan is a member. The Guidebook is slated to be released by AUCD during the 2006 AUCD Conference October 29-November 1 in Washington, DC. "The Mentorship Guide is the perfect tool to improve our existing Family Mentoring experience. Selecting our former Long-Term Trainee in Parent-Family Issues for this position supports our commitment to leadership opportunities for family members who participate in our Oklahoma LEND program" Jan excitedly shares. "Oklahoma LEND has reached out to have an innovative position which can accommodate the extenuating circumstances that so many family members of children with significant health care/disabilities face. Commitment and support from our Oklahoma LEND Program Director, Dr. Mark Wolraich, and our Training Director, Dr. Linda Wilson along with designed flexibility and technology make this possible."

Crissy Stokes is the parent of two wonderful children, one of whom has significant, complex, and long-term health care issues. Her leadership interest is focused on the issues of siblings. Crissy and her husband started a respite program through their church which includes siblings of children with disabilities. She is also working with one of the Oklahoma LEND Family Mentors to develop a state sibling organization. In addition, Crissy coordinates follow-up data collection for the Family Partners component of the OU Child Study Center Interdisciplinary Jumpstart Clinic in which family members partner/team with other disciplines to assess/diagnose developmental disabilities and autism.

For more information about the Family Mentorship Coordinator, contact Jan Moss at jan-moss@ouhsc.edu or at (405) 271-4500 ext 41004.



The Stokes Family:
RJ, Noah, Chrissy and Chloe.

The Commonwealth Fund/Harvard University Fellowship in Minority Health Policy

Joan Y. Reede, MD, MPH, MS, Dean, Office for Diversity and Community Partnership, Harvard Medical School

Supported by The Commonwealth Fund and administered by the Minority Faculty Development Program at Harvard Medical School, this innovative fellowship is designed to prepare physicians, particularly minority physicians, for leadership roles in formulating and implementing public health policy and practice on a national, state, or community level. Five one-year, degree-granting fellowships will be awarded per year. Fellows will complete academic work leading to a Master of Public Health (MPH) degree at the Harvard School of Public Health, and, through additional program activities, gain experience in and understanding of major health issues facing minority, disadvantaged, and underserved populations. CFHUF also offers a Master of Public Administration (MPA) degree at the John F. Kennedy School of Government to physicians possessing an MPH. It is expected that CFHUF will support the development of a cadre of leaders in minority health who are well-trained academically and professionally in public health, health policy, health management, and clinical medicine, as well as actively committed to careers in public service.

As Director of CFHUF, I seek your assistance in informing potential candidates of this opportunity to gain exposure to and understanding of major health issues facing minority and disadvantaged populations. For application materials, information, and other training opportunities, please contact the CFHUF Program Coordinator by telephone at (617) 432-2922; by fax at 617-432-3834; or by e-mail at mfdp_cfhuf@hms.harvard.edu.

EVENTS

AUCD Conference Trainee Scholarships

October 29-November 1, 2006 • Hyatt Regency Hotel • Washington, DC
http://www.aucd.org/aucd_trainees.htm

\$200 AUCD Conference Travel Scholarship

\$200 travel scholarships for 25 trainees to attend the 2006 AUCD Annual Meeting in Washington, DC, on October 29-November 1, 2006 are now available. Applications are due to AUCD via the AUCD trainee website on October 6. Contact cpariseau@aucd.org with questions about the scholarships or the application. To apply for a scholarship, visit the AUCD trainee web page.

Free AUCD Conference Registration

AUCD is offering eight trainees the opportunity to serve as room monitors at the 2006 AUCD Annual Meeting in exchange for free registration, a \$175 value. Applications are due to AUCD via the trainee website on October 6. Contact cpariseau@aucd.org with questions about volunteering or the application. To express interest in volunteering at the AUCD Conference, visit the AUCD trainee web page.

AUCD-APHA Conference Trainee Scholarships

November 4-8, 2006 • Boston, MA
http://www.aucd.org/aucd_trainees.htm

AUCD, in collaboration with the American Public Health Association (APHA) Disability Special Interest Group (Disability SIG), are excited to announce eight new conference scholarship opportunities open to AUCD Network Trainees to attend the 2006 APHA Annual Meeting from November 4-8, 2006 in Boston, MA. All scholarship recipients will have the opportunity to attend the APHA Disability SPIG Forum at the APHA Annual Meeting.

The APHA Annual Meeting & Exposition is a wonderful and important Public Health Educational Forum, drawing about 15,000 participants. With a theme of "Public Health and Human Rights," the APHA meeting will address current and emerging health science, policy, and practice issues to prevent disease and promote health. It is critical that professionals in various disability disciplines understand the issues of children, adults, and seniors with disabilities in areas of health promotion, access to health care services and programs, and health care reform in the public health domain. (See <http://www.apha.org/meetings/>).



Applicants residing in EST and CST time zones are eligible for \$400 scholarships and those residing in MST, PST, AST, and HST are eligible for \$600 Scholarships.

To apply for a scholarship online, visit the AUCD trainee webpage.

Online Applications are due to AUCD by September 29, 2006 5PM EST. Contact Sue Lin (slin@aucd.org) with questions about the scholarships or the application.

2007 Disability Policy Seminar

March 4 - 6, 2007 • The Hyatt Regency Hotel • Washington, DC

The Arc of the United States, United Cerebral Palsy, AAMR, AUCD, and the National Association of Councils on Developmental Disabilities are joining together again to host the 2007 Disability Policy Seminar. It is critical that the disability community and other interested participants from around the country participate in this seminar. Preserving and strengthening federal policies and programs important to people with disabilities is our top priority.

The Disability Policy Collaboration, with these national leading organizations in field of mental retardation, cerebral palsy and related disabilities, brings together state and local executives and affiliates, self-advocates, families, providers and others, for a two-day, intense, public policy discussion/meeting that is focused solely on issues affecting people with disabilities and their families. On the third and final day, participants will go to Capitol Hill to deliver a unified message that Congress and the Administration cannot continue dismantling the benefits and services important to the disability community.

A preliminary seminar agenda, seminar registration information, and hotel registration information for the 2007 Seminar will be available in late fall/early winter.

In addition to the 2007 Seminar, please mark your calendars for the 2008 Disability Policy Seminar (March 2 - 4) at the Hyatt Regency Hotel, 400 New Jersey Avenue, NW, Washington, DC 20001.

EVENTS

Workforce Innovation: Hiring Employees with Disabilities Employer Workshop

October 27, 2006 • Children's Hospital of Philadelphia

The Children's Hospital of Philadelphia LEND, in partnership with the Department of Diversity and Inclusion, is presenting an employer conference to inform and educate local companies about employment of people with disabilities.

The conference, "Workforce Innovation: Hiring Employees with Disabilities" will be held at The Children's Hospital of Philadelphia on Friday, Oct. 27, 2006. The day's program includes information by respected leaders in the field, highlights from a successful program run by Cincinnati Children's Hospital, and presentations from employers as well as employees with disabilities about experiences and practices that are successful. People interested in attending the conference should contact Megan DiTizio, LEND Program Manager, at (215) 590-7466 or ditizio@email.chop.edu for more information.

Chronic Illness and Disability: Transition from Pediatric to Adult-Based Care Conference

November 2-3, 2006 • Texas Medical Center • Houston, TX

www.ome.bcm.tcm.edu • Baylor College of Medicine and LEAH Program

SAVE THE DATE

BCM Baylor College of Medicine
Office of Continuing Medical Education
Houston, Texas

Announces the 7th Annual

**Chronic Illness and Disability:
Transition from Pediatric to Adult-Based Care**

Thursday – Friday, November 2-3, 2006
Edwin Hornberger Conference Center
Texas Medical Center
2151 West Holcombe Boulevard at H. Pressler
Houston, Texas 77030-3303

presented by
Baylor College of Medicine, Department of Pediatrics, Houston, Texas

Supported by a grant from Health Resources and Services Administration, Maternal and Child Health Bureau,
grant #271MAC00011

There is a great need on the part of youth and young adults with chronic illness and/or disabilities, their families, and their healthcare providers to improve the transition from pediatric to adult-based medical services. Leading experts in the field will discuss the current state of transition from pediatric to adult-based care, highlighting barriers and proposed solutions to providing this care.

For further information, visit the conference website or call (713)798-8237.

Bridging the Gap between Pediatric and Adult Care

October 12-13, 2006 • Mount Royal Centre • Montreal, Quebec, Canada

<http://www.pedscourses-mch-mcgill.ca/transitions/>

The success of parents, patients, health professionals, administrators, and researchers in dealing with complex pediatric problems has happily led to a group of new patients who are surviving and graduating to the adult health care system with hopes and dreams of a productive future.

However, these individuals, who still have complex needs, face a challenge in leaving behind the highly specialized support they received in the pediatric system. In addition, physicians in the adult health care system may not be familiar with these conditions which originate during childhood.

Are the pediatric teams preparing their adolescent patients well for the transition? Is the adult health care system ready for them? "Bridging the Gap Between Pediatric and Adult Care" is YOUR opportunity to become involved in this new health challenge.

If you are interested in this exciting new area of pediatric/adult health transition, this is the conference that will get you in on the ground floor. Not only will you learn a great deal about the specific needs of these patients as they enter adulthood, but you will also get a chance to provide your input to the individuals who are going to move this field forward for our patients.

RESOURCES

Policy Statement Recommends Developmental Surveillance at Every Well-Child Visit

<http://aappolicy.aappublications.org/cgi/content/abstract/pediatrics;118/1/405?etoc>

Identifying Infants and Young Children with Developmental Disorders in the Medical Home: An Algorithm for Developmental Surveillance and Screening provides a strategy to support health professionals in establishing a pattern and practice for addressing developmental concerns in children from birth through age 3. The American Academy of Pediatrics' policy statement, published in the July 2006 issue of *Pediatrics*, presents a 10-step algorithm in both text and flowchart formats. Selected steps include eliciting and attending to parents' concerns, maintaining a developmental history, making accurate and informed observations of the child, identifying the presence of risk and protective factors, and documenting the process and findings.

Information about implementing the tool, such as choosing developmental screening tools, incorporating surveillance and screening in the medical home, and screening payment is also provided. The policy statement concludes with a summary and 15 recommendations for the medical home, policy and advocacy, and research and development. The policy statement, intended for use by pediatric health professionals in making developmental surveillance a component of every preventive care visit, is available at <http://aappolicy.aappublications.org/cgi/content/abstract/pediatrics;118/1/405?etoc>.

Transition Resources

Adolescent Resources Division of USF

Janet Hess • 813-653-3279

The following resources are available for download or viewing online:

- Health Care Transition Information and Resource Guide in English, Spanish, Braille and large print.
- High School Curriculum: What's Health Got To Do With Transition? Teacher's guide and student curriculum available.
- Project Evaluation Report: A Demonstration Model for School-Based Health Care Transition Education.

HRSA Website on Transnational Competence

<http://www.hrsa.gov/culturalcompetence/>

HRSA has unveiled a new website on transnational competence. This user-friendly site highlights approximately 40 HRSA-supported projects on the critical subject of serving ethnoculturally and socially diverse groups. This page:

- Serves as a one-stop-shop for health care providers wishing to learn about HRSA's progress in improving culturally competent healthcare.
- Profiles the diverse approaches taken by HRSA-funded activities and programs in areas such as assessment, culture and language, specific diseases, health professions, research, special populations, technical assistance, training, and web-based learning.
- Was developed by HRSA's Office of Minority Health and Health Disparities (OMHHD) with important input from the HRSA Cultural Competence Committee. This Committee consists of representatives from HRSA bureaus and offices that help ensure that HRSA programs integrate cultural competence into health services and health professions education.

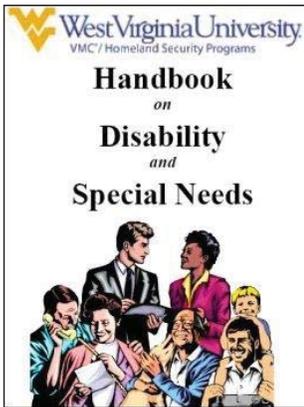
RESOURCES

Handbook on Disability and Special Needs

<http://www.cedwvu.org/programs/dbtac/hrsabrochure/>

One of the most important roles of local government is to protect their citizens from harm, including helping people prepare for and respond to emergencies. Making local government emergency preparedness and response programs accessible to people with disabilities is a critical part of this responsibility. Making these programs accessible is required by the Americans with

Disabilities Act of 1990 (ADA).



VMC®/Homeland Security Programs and the Center for Excellence in Disabilities at West Virginia University, in cooperation with Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services, are engaged in a project to study and make planning recommendations for special needs populations in bioterrorism events and other disasters. This handbook is intended to be used by course designers, emergency planners, and related groups to provide a basic level of knowledge on disability and special needs.

If you are responsible for your community's emergency planning or response activities, you should involve people with disabilities in identifying needs and evaluating effective emergency management practices. Issues that have the greatest impact on people with disabilities include: notification, evacuation, emergency transportation, sheltering, access to medical care and medications, access to their mobility devices or service animals while in transit or at shelters, and access to information.

Handbook chapters include: Special Needs and Emergencies, Disability Etiquette, Web Sites and Online Courses, Resources and Links, and Web Accessibility Validators.

Satisfaction with Primary Health Care Received by Families of Children with Developmental Disabilities

July, 2006 • Journal of Pediatric Health Care • www.jpedhc.org

In this study by members of the Strong Center for Developmental Disabilities LEND in Rochester, NY, the objective was to evaluate the perceptions of families of children with developmental disabilities regarding their primary care physicians and to determine if differences exist for different conditions. One hundred twenty-one families of children with autism, physical disabilities and mental retardation responded to mailed surveys. Families rated physicians highest on their ability to keep up with new aspects of care and on their sensitivity to the needs of children. Parents had the lowest ratings for the primary care physicians' ability to put them in touch with other parents, understanding of the impact of the child's condition on the family, ability to answer questions about the child's condition, and information and guidance for prevention. Physicians' knowledge about complementary and alternative medicine and their qualifications to manage developmental disabilities ranked worse than neutral. Families with a child with autism had more spontaneous negative comments and rated their primary care physicians lower on several aspects of care. They requested more information on complementary and alternative medicine and more support in the community.

To read more, visit the Journal of Pediatric Health Care online at www.jpedhc.org, or see the Journal of Pediatric Health Care. (2006) 20, 245-252.

Do you wonder what projects are undertaken by other LEND and UCEDD programs? Have you ever needed an idea for a community activity? Do your trainees ask you about projects completed by trainees at other programs? Have you wished for a list of other programs' initiatives on a certain topic?

Search the NIRS database

for all products and publications by all LEND and UCEDD programs! The search function allows you to define your own parameters: any fiscal year and any keywords.

<http://www.aucd.org/nirs/db/search/index.cfm>

• *Special Supplement* •

AUCD Trainee Orientation 2006-2007

Introduction

As a trainee, you may have a lot of questions about your program, the AUCD network and the training opportunities which are available to you. This orientation packet is designed to introduce you to the AUCD network and all the unique benefits of being a trainee member of AUCD.

What is AUCD?

The Association of University Centers on Disabilities (AUCD) is a membership organization comprised of university based entities. Membership in AUCD is open to the following groups and includes their employees and trainees:

- University Centers for Excellence in Developmental Disabilities (UCEDD) funded by the Administration on Developmental Disabilities (ADD)
- Leadership Education in Neurodevelopmental Disabilities (LEND) Programs funded by the Maternal and Child Health Bureau (MCHB)
- Developmental Disabilities Research Centers (DDRC), most of which are funded by the National Institute for Child Health and Development (NICHD)

AUCD Vision

AUCD envisions a future where all persons, including those living with developmental and other disabilities, are fully integrated and participating members of their communities. We envision a future where culturally appropriate supports are available across the life span to individuals and families; supports that lead to independence, productivity, and satisfying quality of life.

AUCD Mission

The mission of AUCD is to advance policy and practice for and with people living with developmental and other disabilities, their families, and communities by supporting our members as they engage in research, education, and service that further independence, productivity and satisfying quality of life.

AUCD Values

AUCD values the participation of people living with disabilities, family members, and a culturally diverse membership in its governance and its programs. The network promotes the principles of self-determination, family-centered care, and cultural competence in disability services and supports throughout the life span.

AUCD members represent every US state and territory and include 67 UCEDDs, 35 LENDs, and 19 DDRCs

64 UCEDDs

- The Developmental Disabilities Assistance and Bill of Rights Act authorizes the ADD to improve service systems for individuals with developmental disabilities and other purposes. One way this legislation is implemented is through the grants that establish and maintain UCEDDs.
- UCEDDs in every US state and territory positively affect the lives of individuals with developmental disabilities and their families by increasing their independence, productivity, and integration into communities. They have four broad tasks: conduct interdisciplinary training, promote community services (including community training, technical assistance, and direct services), conduct research projects, and disseminate information.

35 LENDs

- Leadership Education in Neurodevelopmental and Related Disabilities programs are funded through MCHB to provide long-term, graduate level interdisciplinary training in maternal child health to health and allied health professionals.
- LENDs develop trainees' leadership potential to improve the health status of infants, children, and adolescents with or at risk for neurodevelopmental and related disabilities and to enhance the systems of care for these children and their families.
- The 35 LEND Programs in 28 states and DC provide critically needed leadership and clinical training to professionals.

19 DDRCs

- DDRCs are a national resource that grew out of Congress' mandate in 1963 to establish centers of excellence in mental retardation and developmental disabilities research.
- DDRCs represent the nation's first sustained effort to prevent and treat disabilities through biomedical and behavioral re-

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AUCD Trainee Orientation 2006-2007

search, and are the world's largest concentration of scientific expertise in the fields of intellectual and developmental disabilities.

- The scope of the research conducted at the Centers encompasses every known major dimension of mental retardation.

Together these three networks are the major source of research, education, and service in the field of developmental disabilities in the country. Many of these programs are combination programs, where one university or city supports two or even three AUCD programs. In FY2006, the AUCD network saw nearly 89,000 clients in Center clinics and over 69,000 in the community. Additionally, over 812,000 people participated in community or continuing education programs organized by AUCD programs.

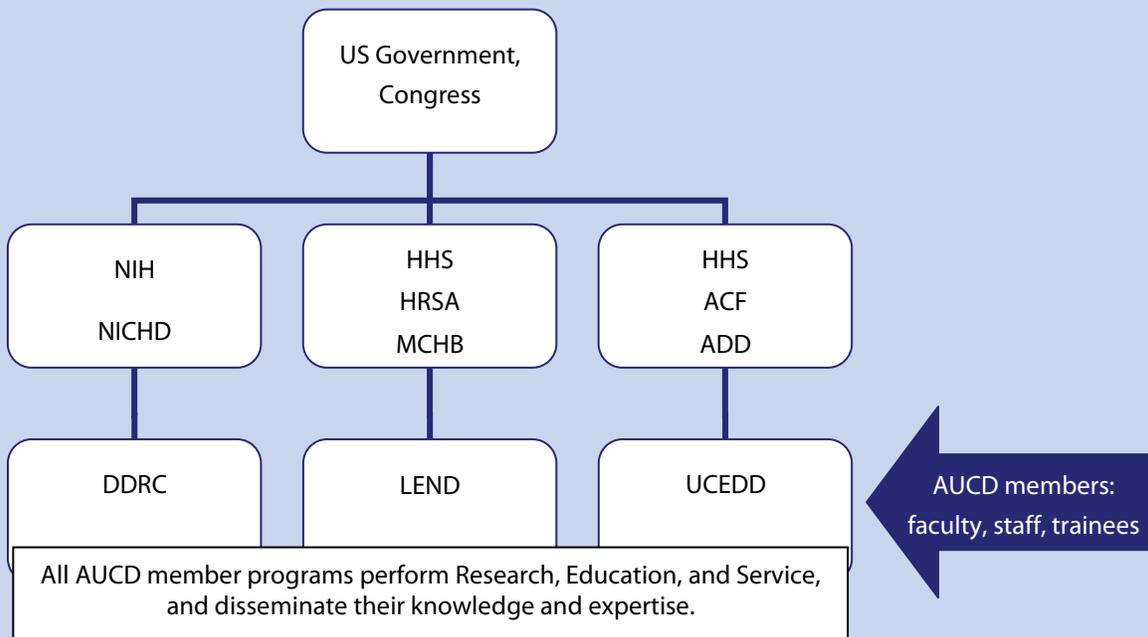


AUCD supports its national network of university centers by providing:

- Leadership on major social problems affecting children and adults living with developmental or other disabilities or special health needs.
- Advocacy with Congress and executive branch agencies that fund and regulate programs utilized by people with disabilities.
- Networking and partnering with other national organizations to advance the networks' national agendas.
- Promoting communication within its network and with other groups by collecting, organizing, and disseminating data on network accomplishments.

Who is an AUCD trainee?

An AUCD trainee is anyone participating in training in interdisciplinary leadership and developmental disabilities at an AUCD member organization.



• *Special Supplement* •**AUCD Trainee Orientation 2006-2007****What does “trainee” mean?**

“Trainee” is the term used by AUCD and its members to refer to any individual who is receiving preservice training or education at a UCEDD, LEND, or DDRC. Some programs refer to their trainees using different terms, such as student, fellow, or intern.

When AUCD says “trainee”, we are most frequently referring to people who are in contact with their program for 300 or more hours during the course of a school year, or long-term trainees. Typically these trainees are LEND long-term trainees, UCEDD trainees, or UCEDD/LEND research assistants. There are other types of trainees too: Intermediate term trainees are in contact with their program from 40-299 hours and might be a medical fellow on rotation or a part-time student. Short term trainees are in contact with the program for less than 40 hours and are often students at the university who take one class at the program or a community service provider working on CEUs.

How many AUCD trainees are there?

In 2006 there were over 4,300 interdisciplinary long-term trainees in the AUCD network. AUCD trainees come from many backgrounds and represent multiple disciplines as they work together on interdisciplinary teams:

- Audiology
- Family
- Genetics
- Health Administration
- Nursing
- Nutrition
- Occupational Therapy
- Pediatrics
- Pediatric Dentistry
- Physical Therapy
- Psychology
- Social Work
- Special Education
- Speech-Language Pathology

...and more, including assistive technology, disability studies, rehabilitation, pastoral, and law.

What does AUCD do for trainees?

AUCD is invested in the trainees of its network. After completion of the program, trainees will become leaders in the clinical, research, service, education, policy, and administration that will affect people with developmental disabilities.

AUCD attempts to contribute to the development of this next generation of leaders by connecting them with the learning and employment opportunities available within the network, providing professional development and networking opportunities, and promoting a community of practice that welcomes graduates of Center programs.

The AUCD Trainee Webpage: www.aucd.org

A section of the AUCD webpage is dedicated solely to trainees. On this page are listed a number of opportunities available to trainees in AUCD that are not available to trainees at other medical schools or universities. These opportunities include:

- **Scholarships and travel stipends to attend national meetings.** AUCD is proud to support trainees to attend meetings at which nationally and internationally recognized speakers present.
- **Interactive communication links to trainees from other network programs.** The Trainee Listserv and Message Board are open to all AUCD trainees. Ask a question about a program, find a trainee with a common research interest, or see what others feel about a topic in the news with the click of a button.
- **Information on what other trainees are doing.** Read highlights and see photos submitted by trainees across the network of their training-related projects or trips.
- **Opportunities to become involved in the AUCD network.** Did you know trainees can serve on AUCD Councils? Visit the trainee website to learn about the six Councils and find out how you can further your leadership by becoming a trainee representative.

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AUCD Trainee Orientation 2006-2007

- **Communications from the AUCD Virtual Trainee.** The Virtual Trainee is a current trainee who works from their home program to encourage communication and linkage among the entire network of trainees. During the course of a year, the Virtual Trainee will send out messages on the listserv and post items on the website, so check back often.
- **Ability to connect with faculty and staff from any program within the AUCD network.** The Trainee Mentor Program is designed to pair interested trainees with faculty from any AUCD network program who has a similar interest. Find out more by visiting the trainee webpage.
- **AUCD newsletters and publications.** Follow the quick links to read the network-wide *AUCDigest* newsletter, the *LEND Links* newsletter, weekly *AUCD Legislative News InBrief*, and more.
- **Employment notices of particular interest to the field.** AUCD continuously posts jobs available at the over 100 AUCD member locations around the country and world. See if one is for you! If you're looking for a Fellowship, we have those too at places like the CDC. Learn more by visiting the trainee web page of www.aucd.org.

By being a trainee at a UCEDD or LEND, you have at your fingertips the resources of the entire AUCD network. These connections and information sources will be invaluable to you as you continue on your career path and to making a difference in the lives of people with disabilities and their families. Be sure to talk with your Director or Training Director to see how you can take full advantage of all AUCD has to offer.



ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES

RESEARCH, EDUCATION, SERVICE

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ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES
RESEARCH, EDUCATION, SERVICE

LEND Links

Editor

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Submissions

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

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

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

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AUCD 2006 Annual Meeting

**Forging New Partnerships for New Challenges
Through Research, Education and Service**

October 29 – November 1, 2006 • Washington, DC

http://www.aucd.org/annual_meeting_2006/index.htm

Highlights and presenters during this year's meeting include:

- **Mike Winer**, a nationally recognized expert on collaboration and creating partnerships
- **Dr. Ed Kame'enui**, the Commissioner of the National Center for Special Education Research, US Department of Education, Institute of Education Sciences
- **Dr. Dick Sobsey**, an internationally acclaimed expert on the issue of violence against people with disabilities
- 40+ concurrent sessions presented by your colleagues
- 60+ presentations at the Poster Session highlighting network programs
- Six in-depth **Skill Building Workshops** and a **Training Symposium**

For complete details please visit our website to access online registration, hotel reservations, a preliminary agenda, and important information for trainees.

You don't want to miss this opportunity to
learn and network with your colleagues.
Register Today!