Leadership Education in Neurodevelopmental and Related Disabilities

Training Our Future Leaders in the Maternal and Child Health Field
Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs were developed by the Health Resources and Services Administration’s (HRSA) Maternal and Child Health Bureau (MCHB) to achieve a vision for the 21st century that,

“All children, youth, and families will live and thrive in healthy communities served by a quality workforce that helps assure their health and well-being.”

LENDs Have a Real-World Impact on the Lives of Children and Families

There are at least 3.8 million children with developmental disabilities, including autism spectrum disorders, in the United States. It is increasingly difficult for people with disabilities to obtain appropriate medical treatment because of the limited number of health care providers, the way that many health care professionals were trained, and other outdated elements of the health care system that fail to meet their needs. LEND Programs are exceptionally qualified to address many of today’s health care shortages through the interdisciplinary training of health care professionals.

LEND Programs have a real-world impact in the lives of children and families with disabilities by:

- Influencing positive attitudes toward children with disabilities;
- Helping pioneer interdisciplinary, inclusive, and integrated systems of care;
- Providing community linkages between scientific discovery and practice;
- Fostering family- and person-centered care;
- Developing new service models and approaches for care;
- Collaborating with state and local agencies;
- Conducting research; and
- Affecting public policy for children with developmental disabilities and their families.
LENDs provide long-term, graduate level interdisciplinary leadership training as well as interdisciplinary services and care. The purpose of the LEND training program is to improve the health of infants, children, and adolescents with or at risk for neurodevelopmental and related disabilities, including autism, and their families. This is accomplished through the training of professionals for leadership roles in the provision of health and related care, continuing education, technical assistance, research, and consultation.

LENDs Train Future Leaders in Maternal and Child Health

Interdisciplinary Leadership Training

Interdisciplinary training is the hallmark of LEND Programs. Faculty and trainees represent 14 core academic disciplines as described in the chart at right. Many LENDs have additional disciplines, including assistive technology, rehabilitation, law, and psychiatry. All LENDs include parents and families of people with special health care needs as paid staff, faculty, consultants, and/or trainees.

LEND programs operate within a university system, many as part of a University Center for Excellence in Developmental Disabilities (UCEDD) or other larger entity, and are commonly affiliated with local university hospitals and/or health care centers. This collaboration provides the programs with expert faculty, facilities, and other resources necessary to provide exceptional interdisciplinary training and services.

LEND curricula encompass education at the master’s, doctoral, and postdoctoral levels, with an emphasis on developing a knowledge and experience base in:
1. Neurodevelopmental and related disabilities, including autism;
2. Family-centered, culturally competent care; and
3. Interdisciplinary and leadership skills.

Traineeships include classroom course work, leadership development, clinical skill building, mentoring, research, and community outreach through clinics, consultations, and the provision of continuing education and technical assistance.

Trainee Core Disciplines

- Audiology ............... 3%
- Family .................. 2%
- Genetics ............... 3%
- Health Administration .. 2%
- Nursing ............... 3%
- Nutrition ............... 3%
- Occupational Therapy ... 4%
- Pediatrics / Medicine ... 26%
- Pediatric Dentistry ... 4%
- Physical Therapy ....... 4%
- Psychology ............ 18%
- Social Work ............ 7%
- Special Education ....... 3%
- Speech-Language Pathology .......... 9%
- Other .................. 9%
The diverse faculty of the LEND Programs are nationally recognized leaders in their fields

Trainees
LEND trainees are the top students in their field who show promise to become leaders in teaching, research, clinical practice, and/or administration and policymaking. Graduates are expected to ultimately affect the nation’s maternal and child health, and leadership training is woven throughout every facet of the LEND Program. Many trainees have directly credited their LEND training to their later career successes. Of the over 2,000 trainees each year, former LEND trainees include:

- The Director of Colorado’s Part C Program;
- A faculty member at a leading state medical school who co-developed a major tool used in outcomes research;
- The Health Policy Staffer for a leading member of the United States Senate; and
- Many LEND Directors; leaders of national and international organizations, state and local agencies; chairs of health-related academic departments in major universities and hospitals; and other influential leadership positions.

In whatever way their leadership is manifested, LEND graduates are uniquely qualified to address the needs of children with special health care needs and their families through clinical services, program administration, and policy development.

Faculty
The diverse faculty of the LEND Programs are nationally recognized leaders in their fields and this collective expertise is what makes LENDs successful. Their research and publications have been disseminated worldwide. In their respective disciplines, these faculty members:

- Mentor students in exemplary MCH public health practice;
- Advance the field through research;
- Provide exemplary clinical services to children and families;
- Develop curricula for interdisciplinary leadership education; and
- Provide continuing education on the latest research and practice to professionals currently in the field.

LENDs Have Many Achievements
As a network, LENDs develop and promote best practices, produce exceptional clinicians and leaders in a variety of disciplines, and further systems change through:

- Interdisciplinary training;
- Leadership skill development;
- Promotion of cultural competence;
- Community outreach and continuing education;
- Policy development;
- Translation of research to practice;
- Provision of technical assistance;
- Collaborative processes; and
- Resource development and dissemination.

“The team approach has been important for Josiah and our family. With Josiah, it was important to find care providers who understood his disabilities and knew how to help him. The interaction between professionals has been especially helpful to us to put the puzzle pieces together and to decide what services and treatments would be best for our son.”

— Monty Gurnsey, Parent, Omaha, NE
“As a LEND trainee I not only learned the value of working with other disciplines, I also learned how to bridge the communication gaps that frequently hinder collaboration... I am a better clinician and researcher because I was a LEND trainee.”

— Amy Elliott, PhD, Research Director
Center for Disabilities, SD

Recent LEND Network Highlights

- Provided continuing education to over 64,000 individuals, including health care professionals and paraprofessionals, family members and caregivers, legislators, and individuals with disabilities.
- Trained nearly 2,000 long-term and intermediate LEND trainees.
- Provided more than 112,000 individuals with special health care needs and disabilities with clinical or community-based services.
- Developed more than 2,100 products and publications about developmental disabilities, including autism.

LENDs are Fundamental to MCHB’s Mission

HRSA’s Maternal and Child Health Bureau (formerly the Children’s Bureau) began its efforts in the 1950’s to identify and treat children with disabilities. Since their inception in the 1960’s, LENDs have long held a crucial role in assuring exemplary assessment and treatment by training leaders in health fields and providing interdisciplinary care. In the 1980s, LEND projects were funded under Title V of the Social Security Act and administered through the MCH Training Program of MCHB. As a result of the Combating Autism Act of 2006, both the LEND and Developmental Behavioral Pediatrics training programs are funded under the Public Health Service Act.

LEND Programs Form a National Network

There are 43 LENDs across the country. Collectively, they form a national network that shares information and resources and maximizes their impact. They work together to address national issues of importance to children with special health care needs and their families, exchange best practices, and develop shared products.

- LENDs have the same overall mission, yet each of the programs has a unique focus and develops individual strengths.
- LENDs come together regionally to address issues specific to their location.
- LENDs also work together nationally to address common concerns, exchange best practices, and develop shared products.

Through their membership in the Association of University Centers on Disabilities (AUCD), LENDs are an integral part of national and international efforts to improve the lives of persons with disabilities their families, and their communities.
About Developmental Disabilities and Autism Spectrum Disorders

What is a Developmental Disability?

Developmental disabilities are a diverse group of severe chronic conditions that are due to mental and/or physical impairments. People with developmental disabilities have challenges with major life activities such as language, mobility, learning, and independent living. Developmental disabilities may be apparent anytime from birth up to 22 years of age and are usually lifelong. Over 6 million individuals in the US have developmental disabilities. A developmental disability, according to the Developmental Disabilities Assistance and Bill of Rights Act, is defined as a severe, chronic disability which:

- Originates at birth or during childhood;
- Is expected to continue indefinitely; and
- Substantially restricts the individual's functioning in several major life activities.

Examples of developmental disabilities include:

- Autism spectrum disorders
- Behavior disorders
- Brain injury
- Cerebral palsy
- Spina bifida
- Fetal alcohol syndrome
- Down syndrome
- Fragile X syndrome
- Intellectual disabilities

People with developmental disabilities benefit from comprehensive, long-term supports. With such services, people with disabilities are able to be more active, productive, and independent.

There are many social, environmental and physical causes of developmental disabilities, although for many a definitive cause is still a scientific challenge yet to be discovered. Common factors causing developmental disabilities include:

- Brain injury or infection before, during or after birth;
- Growth or nutrition problems;
- Abnormalities of chromosomes and genes;
- Babies born long before their expected birth date;
- Poor diet or health care;
- Drug misuse during pregnancy, including alcohol intake and smoking; and
- Child abuse, which can also have a severe effect on a child's socio-emotional development.

LEND trainees are prepared to provide skillful assessment and treatment of developmental disabilities and to engage in the research necessary to demonstrate that their practices are effective.

What are Autism Spectrum Disorders?

Autism spectrum disorders (ASDs) are a group of developmental disabilities defined by significant impairments in social interaction and communication and the presence of unusual behaviors and interests. Many people with ASDs have atypical ways of learning, paying attention, or reacting to sensations. The thinking and learning abilities of people with ASDs can vary from gifted to severely challenged. ASD is a lifelong condition that may be diagnosed before the age of 3. It occurs in all racial, ethnic, and socioeconomic groups and is four times more likely to occur in boys than girls.

ASDs currently include autism, Asperger's syndrome, and pervasive developmental disorder-not otherwise specified. While these conditions may share some of the same symptoms, they differ in terms of age of onset, severity, and appearance.
As many as 1 in 110 children may have an autism spectrum disorder

The rapid growth of the number of children with ASD and other related developmental disabilities is an urgent concern for families, health care professionals, educators, and policy makers.

Early intervention has been demonstrated to greatly improve the development of children with disabilities, and LEND training prepares professionals in evidenced-based practices for the identification, assessment and treatment of children. LEND trainees receive extensive specialized training that focuses on autism and other developmental disorders. This training is critical in addressing the need of children with disabilities and their families.

As a result of the Combating Autism Act of 2006 and the 2011 reauthorization, HRSA’s MCHB has been able to both supplement current LEND programs to expand their training efforts in the field of autism as well as fund additional LEND programs in states that did not have one. These additional resources have increased the number of interdisciplinary professionals who are able to identify, assess, diagnose, and serve children with autism spectrum disorders and other developmental disabilities. Much more needs to be done, but the Combating Autism Act has helped LEND programs begin to better address the challenge of the increased numbers of children with autism.

Members of the LEND Network are Leaders in the Field of Autism and Developmental Disabilities

LENDs have over 40 years of experience in conducting research, providing community education and outreach, and addressing the social, behavioral, and medical concerns for families with autism and other disabilities. Many LEND faculty and former trainees are nationally and internationally recognized experts in autism and other disabilities, and they continue to work with current trainees to broaden the field of knowledge and services available. Over the past year, faculty and staff at LEND programs have:

- Conducted over 44,000 interdisciplinary diagnostic evaluations to confirm or rule out autism or other developmental disabilities;
- Provided over 5,570 technical assistance and consultative to state and local organizations; and
- Published over 338 different autism-specific products, including refereed journal articles, books, book chapters, and public awareness materials.

Collaboration with Others

LENDs work with local, state, national, and international groups to address issues of concern for people with disabilities, their families, and public health officials. Their involvement with the groups below provides avenues for critical collaborations in the field.

- American Academy of Pediatrics
- Association of Maternal and Child Health Programs
- Autism NOW
- Autism Society of America
- Autism Speaks
- Autism Treatment Network
- Centers for Disease Control and Prevention’s National Center on Birth Defects and Developmental Disabilities
- Easter Seals
- Eunice Kennedy Shriver National Institute of Child Health and Human Development
- Family Voices
- Health Resources and Services Administration’s Maternal and Child Health Bureau
- MCHB Interdisciplinary Training Programs, including LEAH, PPC, DBP, SPH, and others
- Merck Foundation
- National Center for Hearing Assessment and Management
- National Professional Development Center on Autism Spectrum Disorders
- Network of Autism Training and Technical Assistance Programs
- National Center for Cultural Competence
- National Youth Leadership Network
- Ohio Center for Autism and Low Incidence
- Society for Developmental and Behavioral Pediatrics
LEND Programs

Alabama — Civician International Research Center
University of Alabama at Birmingham
Birmingham, AL
(205) 934-5471 | www.circ.uab.edu

Alaska — Center for Human Development
University of Alaska Anchorage
Anchorage, AK
(907) 272-8270 | www.uaa.alaska.edu/centerforhumandevelopment/LEND

Arizona — AZ LEND
The University of Arizona
Tucson, AZ
(520) 626-7601 | http://azlend.peds.arizona.edu

Arkansas — Arkansas LEND
Department of Pediatrics
University of Arkansas for Medical Sciences
Little Rock, AR
(501) 343-1836 | www.uams.edu/pediatrics

California — University of Southern California
Center for Excellence in Developmental Disabilities
Los Angeles, CA
(323) 361-2300 | www.uscucd.edu

Colorado — JFX Partners
University of Colorado Denver School of Medicine
Aurora, CO
(303) 724-7673 | www.jfxpartners.org

Florida — Mailman Center for Child Development
University of Miami Miller School of Medicine
Miami, FL
(305) 243-6801
http://peditract.med.miami.edu

Georgia — Center for Leadership in Disability
Georgia State University
Atlanta, GA
(404) 413-1261 | www.clid-gsu.org

Hawaii — Hawaii LEND Program
University of Hawaii College of Education / John A. Burns School of Medicine
Honolulu, HI
(808) 956-3142
Honolulu, HI
(808) 956-3142
http://www2.hawaii.edu/~mchlend/

Illinois — Institute on Disability and Human Development
Department of Disability and Human Development
University of Illinois at Chicago
Chicago, IL
(312) 596-3882 | www.illdhd.org

Indiana — Riley Child Development Center
Indiana University
Indianapolis, IN
(317) 274-8167 | www.child-dev.com

Iowa — Iowa LEND Program
Center for Disabilities and Development
University of Iowa Health Care
Iowa City, IA
(319) 353-8869 | www.uihealthcare.com/cdd

Kansas — Center for Child Health and Development
University of Kansas Medical Center
Kansas City, KS
(913) 584-5600 | www.kumc.edu/childhealthdevelopment

Maryland — Kennedy Krieger Institute
The Johns Hopkins University
Baltimore, MD
(410) 923-9400 | www.kennedykrieger.org

Massachusetts — Institute for Community Inclusion
Children’s Hospital Boston
Boston, MA
(617) 287-4300 | www.communityinclusion.org

Massachusetts — Enine Kennedy Shriver Center
University of Massachusetts UCEED/LEND
Waltham, MA
(781) 842-0228 | www.shriver.org

Minnesota — MN LEND
University of Minnesota
Minneapolis, MN
(612) 234-3000 | http://mned.umn.edu

Missouri — TIPS for Kids
University of Missouri-Columbia
University of Missouri-Kansas City
Columbia, MO
(573) 882-0737 | www.Tips4Kids.org

Nebraska — Monroe-Meyer Institute for Genetics and Rehabilitation
University of Nebraska Medical Center
Omaha, NE
(402) 559-6340 | www.unmc.edu/mmi

Nevada — Nevada Center for Excellence in Disabilities
University of Nevada, Reno
Reno, NV
(775) 784-4921 | http://nced.info/

New Hampshire — New Hampshire MCH LEND Program
Children’s Hospital at Dartmouth
Institute on Disability/UCEDD
University of New Hampshire
Durham, NH
(603) 650-5000 | www.mch.lend.unh.edu

New Mexico — Center for Development and Disability
University of New Mexico Health Sciences Center
Albuquerque, NM
(505) 272-3025 | www.ucdd.unm.edu/NewMCLEND

New York — Strong Center for Developmental Disabilities
University of Rochester
Golisano Children’s Hospital at Strong
Rochester, NY
(585) 275-0355
www.urmc.rochester.edu/childrens-hospital/developmental-disabilities/fellowships/LEND

New York — Westchester Institute for Human Development
School of Public Health
New York Medical College
Valhalla, NY
(914) 493-8175 | www.wihi.org

North Carolina — North Carolina LEND Program
Carolina Institute for Developmental Disabilities
University of North Carolina School of Medicine
Chapel Hill, NC
(919) 966-5171 | www.cdunc.edu

Ohio — Cincinnati Children’s Division of Developmental and Behavioral Pediatrics LEND Program
University of Cincinnati
Cincinnati, OH
(513) 636-8338
http://www.cincinnatichildrens.org/LEND

Ohio — Nisonger Center
The Ohio State University
Columbus, OH
(614) 292-6816
http://nisonger.osu.edu/LEND/

Oklahoma — Oklahoma LEND
University of Oklahoma Health Sciences Center
Oklahoma City, OK
(405) 271-5700
http://www.uoahs.com/oidd/LEND/

Oregon — Oregon Institute on Disability and Development
Oregon Health & Science University
Portland, OR
(503) 494-2734 | www.ohsu.edu/oidd/LEND/

Pennsylvania — The Children’s Hospital of Philadelphia
Philadelphia, PA
(215) 596-7468 | www.chop.org/CHOP-LEND

Pennsylvania — The UCIDC Center
University of Pittsburgh
Pittsburgh, PA
(412) 692-6300 | (412) 692-6538
www.ucidc.org

South Carolina — SC LEND
Medical University of South Carolina
Charleston, SC
(843) 792-1414

South Dakota — Center for Disabilities
Sanford School of Medicine of the University of South Dakota
Sioux Falls, SD
(605) 337-1439 | www.usd.edu/co/ds/LEND

Tennessee — Coaching Center for Developmental Disabilities
University of Tennessee Health Science Center
Memphis, TN
(901) 448-8511 | www.utmenc.urmc.edu/bccd

Tennessee — Mid-Tennessee Interdisciplinary Instruction in Neurodevelopmental Disorders
Vanderbilt University
Nashville, TN
(615) 930-1104
http://cc.vanderbilt.edu/site/LEND/

Texas — LoneStar LEND
University of Texas Health Science Center at Houston
Houston, TX
(713) 500-3637 | www.LoneStarLEND.org

Utah — Utah Regional Leadership Education in Neurodevelopmental Disabilities (URLEND)
University of Utah
Salt Lake City, UT
(801) 586-1017 | www.ureld.org

Vermont — VT Interdisciplinary Leadership Education for Health Professionals
University of Vermont
Burlington, VT
(802) 656-0204 | www.uvm.edu/~vtilehp

Virginia — Partnership for People with Disabilities
Virginia Commonwealth University
Richmond, VA
(804) 828-0073
www.vcu.edu/partnership/valend/

Washington — LEND Program, Clinical Training Unit
Center on Human Development and Disability
University of Washington
Seattle, WA
(206) 685-1350
http://depts.washington.edu/LEND

West Virginia — West Virginia University Center for Excellence in Disabilities
WVU Robert C. Byrd Health Sciences Center
Morgantown, WV
(304) 293-4692 | www.cedwvu.org

Wisconsin — Waisman Center
University of Wisconsin-Madison
Madison, WI
(608) 293-1656
www.waisman.wisc.edu/mchlend/

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www.aucd.org | www.aucd.org/LEND | aucdinfo@aucd.org | 301-588-8252
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