



ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES
THE LEADERSHIP, EDUCATION, ADVOCACY & RESEARCH NETWORK



LEND

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 for,

"An America where all children and families are healthy and thriving, and have a fair shot at reaching their fullest potential."

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 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of the limited number of health care providers, the way that many health care professionals were trained, and other outdated elements of the health care system that fail to meet their needs.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 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.

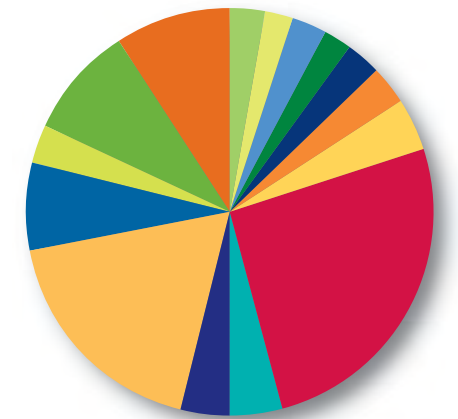
LEND programs operate within a university system, many as part of a University Center for Excellence in Developmental Disabilities (UCEDD) or other larger entity, and are commonly affiliated with local university hospitals and/or health care centers. This collaboration provides the programs with expert 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 | 4% |
| ■ Family | 2% |
| ■ Genetics | 1% |
| ■ Nursing | 3% |
| ■ Nutrition | 4% |
| ■ Occupational Therapy . . . | 5% |
| ■ Pediatrics / Medicine . . . | 23% |
| ■ Pediatric Dentistry | 2% |
| ■ Physical Therapy | 4% |
| ■ Psychology | 16% |
| ■ Self-Advocate | 4% |
| ■ Social Work | 5% |
| ■ Special Education | 4% |
| ■ Speech-Language Pathology | 7% |
| ■ Other | 4% |

LEND

The diverse faculty of the LEND Programs are nationally recognized leaders in their fields

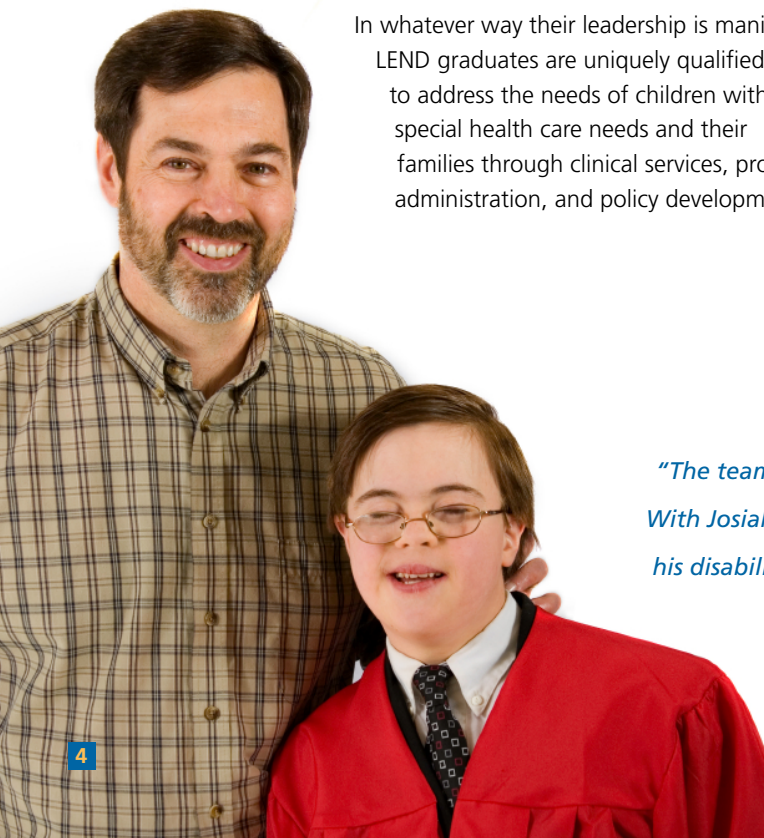


Trainees

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 3,000 trainees graduating from the program each year, former LEND trainees include:

- The Director of a state 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.



"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 pieces together and to decide what services and treatments would be best for our son."

— Monty Gurnsey, Parent

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.

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.



"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

Recent Year-end LEND Network Highlights

- Provided continuing education to over 220,000 individuals, including health care professionals and paraprofessionals, family members and caregivers, legislators, and individuals with disabilities.
- Trained nearly 2,900 long-term and intermediate LEND trainees.
- Provided more than 166,000 individuals with special health care needs and disabilities with clinical or community-based services.
- Developed more than 3,600 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 MCHB's Division of MCH Workforce Development. Since 2006, both the LEND and Developmental Behavioral Pediatrics training programs have been funded under the Autism Collaboration, Accountability, Research, Education and Supports--or Autism CARES--Act.

LEND Programs Form a National Network

There are 52 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.

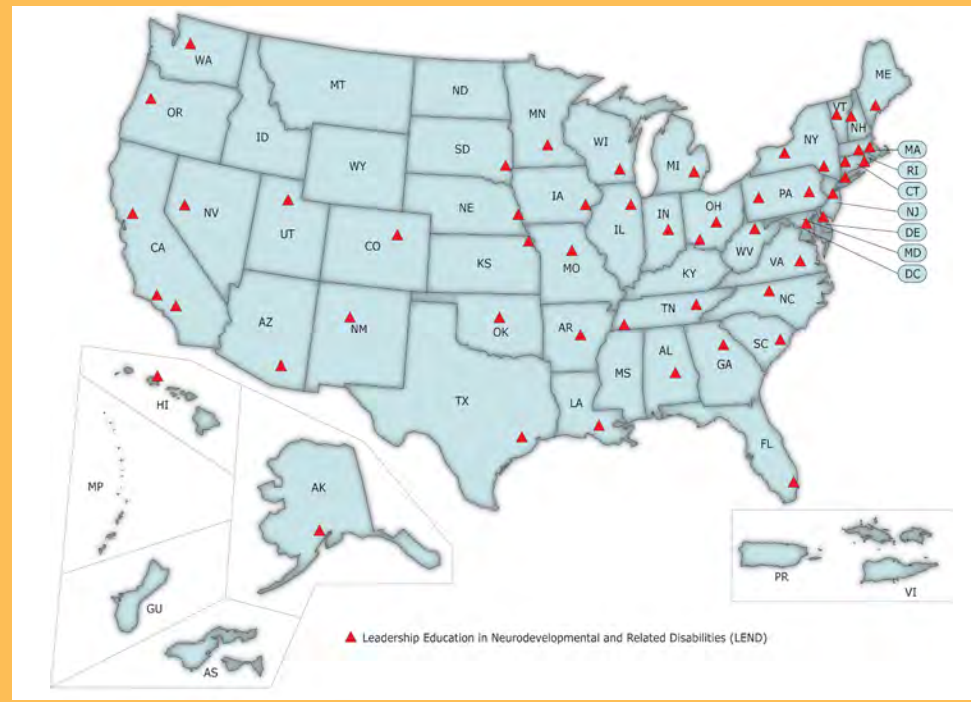
LEND trainees are prepared to provide skillful assessment and treatment of developmental disabilities and to engage in the research necessary to demonstrate that their practices are effective.

What is Autism Spectrum Disorder?

According to the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), Autism Spectrum Disorder (ASD) is a developmental disability characterized by:

- Differences in social communication and social interaction across multiple contexts (e.g. social-emotional reciprocity, nonverbal communicative behaviors, understanding relationships); and
- Restricted, repetitive patterns of behavior, interests, or activities (e.g. repetitive motor movements, inflexible adherence to routines, hyper- or hyporeactivity to sensory input).

The Centers for Disease Control and Prevention (CDC) reports that about 1 in 59 children has been identified as having ASD; it occurs in all racial, ethnic, and socioeconomic groups and is more than four times more likely to occur in boys than girls. It is a lifelong condition that may be diagnosed before the age of three. People with ASD have a wide range of cognitive abilities and support needs, hence the need for individualized approaches to care. While many people with ASD share some of the same symptoms, they differ greatly in terms of age of onset, severity, and appearance.



As many as 1 in 59 children may have Autism Spectrum Disorder

The rapid growth of the number of children with ASD and other related developmental disabilities is a 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 **Autism Collaboration, Accountability, Research, Education and Supports, or CARES, Act**, formerly known as the Combating Autism Act, 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 this legislation has helped LEND programs 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 50 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. In the past year, faculty and staff at LEND programs:

- Conducted over 105,500 interdisciplinary diagnostic evaluations to confirm or rule out autism or other developmental disabilities;
- Provided over 3,400 technical assistance and consultative sessions to state and local organizations; and
- Published over 510 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
- Autistic Self Advocacy 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
- Self Advocates Becoming Empowered
- Society for Developmental and Behavioral Pediatrics

Over 6 million individuals in the US have developmental disabilities.

LEND Programs

Alabama – Civitan International Research Center
University of Alabama at Birmingham
Birmingham, AL, (205) 934-5471
www.uab.edu/civitanpartners

Alaska – Center for Human Development
University of Alaska Anchorage
Anchorage, AK, (907) 272-8270
www.alaskachd.org

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

Arkansas – Partners for Inclusive Communities
University of Arkansas at Fayetteville
Little Rock, AR
(501) 301-1100 | www.UofAPartners.uark.edu

California – CA LEND
Children's Hospital Los Angeles
University of Southern California
Los Angeles, CA, (323) 361-2300
www.USCucedd.org

California – The Northern CA LEND Project
University California Davis, MIND Institute
Sacramento, CA, (916) 703-0264
www.ucdmc.ucdavis.edu/mindinstitute/education/lend/

California – UC-LEND
UCLA-UCR, Los Angeles, CA
(310) 825-5797 | www.uc-lend.org

Colorado – JFK Partners
University of Colorado Denver
Aurora, CO
(303) 724-5266 | www.jfkpartners.org

Connecticut – UConn Center for Excellence in Developmental Disabilities
University of Connecticut, Farmington, CT
(860) 679-1500 | www.uconnucedd.org

Delaware – Center for Disabilities Studies
University of Delaware
Newark, DE, (302) 831-6974
www.udel.edu/cds

Florida – Mailman Center for Child Development
University of Miami Miller School of Medicine
Miami, FL, (305) 243-6801
<http://mailmancenter.org>

Georgia – Center for Leadership in Disability
Georgia State University, Atlanta, GA
(404) 413-1281 | www.cld-gsu.org

Hawaii – Hawaii LEND Program
John A. Burns School of Medicine
University of Hawaii at Manoa
Honolulu, HI, (808) 369-1240
<http://blog.hawaii.edu/mchlend/>

Illinois – University of Illinois LEND
University of Illinois at Chicago
Chicago, IL, (312) 996-8905
www.illinoislend.org

Indiana – Riley Child Development Center
Indiana University, Indianapolis, IN
(317) 944-8167 | <http://pediatrics.iu.edu/sections-and-faculty/child-development/>

Iowa – Iowa LEND Program
Center for Disabilities and Development
Iowa City, IA, (319) 353-8869
<https://uihc.org/ucedd/iowa-leadership-education-neurodevelopmental-and-related-disabilities-project>

Kansas – Center for Child Health and Development
University of Kansas Medical Center
Kansas City, KS
(913) 588-5900 | www.kumc.edu/cchd/

Louisiana – Louisiana UCEDDERS
Louisiana State University Health Sciences Center
New Orleans, LA
(504) 556-7585 | www.hdc.lsuhscc.edu

Maine – The Maine LEND Program
University of New England, Portland, ME
(207) 221-4587 | www.une.edu/LEND

Maryland – Kennedy Krieger Institute
The John Hopkins University, Baltimore, MD
(443) 923-9400 | www.kennedykrieger.org

Massachusetts – Eunice Kennedy Shriver Center
University of Massachusetts Medical School
Charlestown, MA, (774) 455-5433
www.umassmed.edu/shriver

Massachusetts – Institute for Community Inclusion
Children's Hospital Boston, Boston, MA
(617) 355-6506 | www.childrenshospital.org/ici

Michigan – Developmental Disabilities Institute
Wayne State University, Detroit, MI
(313) 577-2654 | <http://ddi.wayne.edu>

Minnesota – MN LEND
Institute on Community Integration
University of Minnesota, Minneapolis, MN
(612) 301-3438 | <http://lend.umn.edu>

Missouri – TIPS for Kids
University of Missouri-Columbia
Columbia, MO
(573) 882-0757 | www.Tips4kids.org

Nebraska – Munroe-Meyer Institute for Genetics and Rehabilitation
University of Nebraska Medical Center
Omaha, NE, (402) 559-6430
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 LEND Program
Dartmouth-Hitchcock Medical Center
Children's Hospital at Dartmouth
Lebanon, NH, (603) 650-5000
<http://iod.unh.edu/projects/MCH-LEND.html>

New Jersey – The Boggs Center on Developmental Disabilities
Rutgers Robert Wood Johnson Medical School
New Brunswick, NJ, (732) 235-9300
<http://rwjms.rutgers.edu/boggscenter>

New Mexico – Center for Development and Disability
Albuquerque, NM (505) 272-3025
<http://cdd.unm.edu/NMLEnd/>

New York – Rose F. Kennedy Center LEND
The Teaching Hospital of Albert Einstein College of Medicine, Montefiore Medical Center, Bronx, NY
(718) 839-7162 | www.einstein.yu.edu

New York – Westchester Institute for Human Development
Center on Disability and Health, New York Medical College, Valhalla, NY
(914) 493-8204 | www.wihd.org

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

North Carolina – Carolina Institute for Developmental Disabilities
The University of North Carolina at Chapel Hill
Chapel Hill, NC
(919) 966-5171 | www.cidd.unc.edu

Ohio – LEND Program at Cincinnati Children's Hospital
University of Cincinnati, Cincinnati, OH
(513) 803-3627 | www.uclend.org

Ohio – Nisonger Center LEND
The Ohio State University, Columbus, OH
(614) 688-8472 | <http://nisonger.osu.edu/LEND/>

Oklahoma – Oklahoma LEND
University of Oklahoma Health Sciences Center
Oklahoma City, OK, (405) 271-5700
www.oumedicine.com/body.cfm?id=1516

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

Pennsylvania – Children's Seashore House
The Children's Hospital of Philadelphia
University of Pennsylvania School of Medicine
Philadelphia, PA, (215) 590-7466
<http://doiop.com/CHOP-LEND>

Pennsylvania – LEND Center of Pittsburgh
University of Pittsburgh, Children's Hospital of Pittsburgh, Pittsburgh, PA
(412) 692-6538 | www.lend.pitt.edu

Rhode Island – Rhode Island LEND
Rhode Island Hospital
Providence, RI, (401) 444-4003
www.lifespan.org

South Carolina – SC LEND
Medical University of South Carolina
Charleston, SC, (843) 876-1511
www.musc.edu/sclend

South Dakota – Center for Disabilities
Sanford School of Medicine of the University of South Dakota, Sioux Falls, SD
(605) 357-1439 | www.usd.edu/cd/sdlend

Tennessee – Boling Center for Developmental Disabilities
University of Tennessee Health Science Center
Memphis, TN
(901) 448-6511 | www.utsc.edu/bccdd/

Tennessee – Vanderbilt LEND
Vanderbilt University, Nashville, TN
(615) 936-1104
<http://kc.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 LEND
University of Utah, Salt Lake City, UT
(801) 585-1017 | www.urlend.org

Vermont – VT LEND
University of Vermont, Burlington, VT
(802) 656-0204 | www.uvm.edu/medicine/vtlend

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

Washington – University of Washington LEND
Center on Human Development and Disability
University of Washington
Seattle, WA, (206) 685-1350
<http://depts.washington.edu/lend>

West Virginia – Center for Excellence in Disabilities
West Virginia University, Morgantown, WV
(304) 293-4692 | www.cedwvu.org

Wisconsin – Waisman Center
University of Wisconsin-Madison
Madison, WI, (608) 263-1656
www.waisman.wisc.edu/mchlend/



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