

MATERNAL AND CHILD HEALTH LEADERSHIP EDUCATION IN NEURODEVELOPMENTAL AND RELATED DISABILITIES (LEND)

MCH Training Program

PROGRAM HISTORY AND STRATEGY

Children with special health care needs (CSHCN) have been of particular concern to the Children's Bureau, and later to the Maternal and Child Health Bureau (MCHB), since the Children's Bureau's inception. In the early 1950s, the chief of the Children's Bureau made it a priority to learn more about



children with mental retardation. The Bureau initially supported four demonstration projects that developed interdisciplinary clinical services for children with mental retardation. By 1957, states were developing new diagnostic, consultation, and education (D & E) clinics. In several of these clinics, health professionals found that up to half of the children initially diagnosed as having mental retardation did not. In 1960, the Children's Bureau began providing grants to institutions of higher learning to train interdisciplinary teams to serve children with mental retardation.

The 1960s and 1970s were periods of rapid advancement in knowledge about children with mental retardation. In 1963, President Kennedy established the first University Affiliated Facility (UAF) to research and treat mental retardation, as well as train providers of services to persons with mental retardation. The Children's Bureau supported

training for persons providing services in the newly constructed UAFs. By 1969, most training and core support of UAFs were provided by the Children's Bureau; as a result, much of the training focused on children. Training and research about children with mental retardation advanced hand in hand. It was discovered that some forms of mental retardation—those caused by phenylketonuria (PKU) and rubella (German measles), for example—were preventable; other forms could be dramatically improved through early and continuous intervention services, such as those provided at UAFs.

By the 1980s and 1990s, families and clinicians were partnering to prevent developmental disabilities, when possible, through early intervention, and to lessen the effects of those that could not be prevented entirely. Early intervention requires health professionals who are knowledgeable about children with disabilities, who can help families understand the nature of the child's disability, who determine a medical diagnosis when possible, who assess the child's functional level, and who assist the family in learning about and accessing a wide variety of services. Increasingly, health professionals now strive to provide these services in a family-centered, community-based, coordinated fashion. By 1987, the UAFs had become university-affiliated programs (UAPs), reflecting the fact that they were much more than the physical facilities initially supported by the legislation. In 1994, MCHB changed the name of its

grant program from UAPs to Maternal and Child Health Leadership Education in Neurodevelopmental and Related Disabilities (LEND). LEND grants provide interdisciplinary training to enhance the clinical expertise and leadership skills of health professionals dedicated to caring for children with disabilities.

PROGRAM CHARACTERISTICS

The purpose of the LEND program is to improve the health of children who have, or are at risk for developing, neurodevelopmental or related disabilities by preparing trainees from a wide variety of professional disciplines to assume leadership roles and to ensure high levels of clinical competence. LEND program objectives include the following: (1) advancing the knowledge and skills of the full range of child health professionals to improve health care delivery systems for children with developmental disabilities; (2) providing high-quality education training for health professionals; (3) providing a wide range of health professionals with the skills needed to foster a community-based partnership of health resources and community leadership; and (4) promoting innovative practice models that enhance cultural competency, partnerships between disciplines, and family-centered approaches to care.

Funds are available to support programs that focus on these objectives at the regional level, including programs with an expanded scope that address both regional and national needs. The programs focus on identifying the special needs of children and families that are specific to a clearly defined area of the country. They collaborate regularly with the myriad of health, education, and social service agencies serving children with developmental disabilities. LEND training projects also function as regional and national resources by conducting

continuing education activities, providing technical assistance and consultation, and developing and disseminating educational materials.

HIGHLIGHTS

Faculty. The LEND program provides clinically based graduate and postgraduate leadership training for health professionals in the fields of neurodevelopmental and related disabilities. Faculty and trainees in LEND projects represent 11 disciplines, including developmental pediatrics, nursing, public health social work, nutrition, speech-language pathology, audiology, pediatric dentistry, psychology, occupational therapy, physical therapy, and health administration. Parents of children with neurodevelopmental disabilities are also included as program faculty or paid consultants.

Trainees. The trainees enrolled in the program are working toward a graduate degree or are enrolled in a postgraduate program in one of the represented disciplines, with an emphasis on infants, children, and adolescents with special health care needs. The LEND program itself is part of a freestanding unit within the university; it draws trainees and faculty from individual departments or colleges within the university. Degrees for the trainees are conferred by their home departments or colleges.

Curriculum. The LEND program curriculum includes graduate education at the master's, doctoral, and postdoctoral training levels, with an emphasis on developing a knowledge and experience base that includes the following: (1) knowledge of all aspects of neurodevelopmental and related disabilities, (2) knowledge of the family environment, and (3) acquisition of interdisciplinary team skills. Course content and philosophy aim to prepare trainees to assume leadership roles in the develop-

ment, improvement, and integration of health care systems for children with special health care needs in culturally appropriate, community-based, family-centered settings. Traineeships include classroom course work, clinical skills building, mentoring, and outreach to the community through clinics, continuing education, consultation, and technical assistance.

By providing interdisciplinary long-term training, by developing exemplary clinical service models, and by reaching out to the community through consultation, technical assistance, and continuing education, the LEND program has made significant strides toward developing comprehensive, coordinated services for children with developmental disabilities and for their families.

PROGRAM PROFILE

- In FY 1999, the LEND program funded 35 projects, with annual grant awards totaling about \$18.2 million.
- The grant awards range from \$300,000 to \$1.2 million per year, with a mean award amount of \$520,000.

For additional information about the LEND projects, please visit <http://www.aauap.org>.

Present Grant Recipients

STATE	GRANTEE
AL	University of Alabama at Birmingham
AR	University of Arkansas
CA	University of Southern California

CO	University of Colorado Health Sciences Center
DC	Georgetown University
FL	University of Miami
HI	University of Hawaii
IA	University of Iowa
IN	Indiana University
KS	University of Kansas
MA	Children's Hospital, Boston Massachusetts General Hospital
MD	Johns Hopkins University
MO	University of Missouri
NE	University of Nebraska
NC	University of North Carolina at Chapel Hill
NH	Dartmouth College
NM	University of New Mexico
NY	Albert Einstein College of Medicine University of Rochester Westchester Institute for Human Development
OH	University of Cincinnati Ohio State University
OK	University of Oklahoma
OR	Oregon Health Sciences Center
PA	Children's Seashore House University of Pittsburgh
SD	University of South Dakota
TN	University of Tennessee, Memphis Vanderbilt University Medical Center
VA	Virginia Commonwealth University
VT	University of Vermont
WA	University of Washington
WI	University of Wisconsin-Madison
WV	West Virginia University

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