LENDing a Helping Hand to Children with Neurodevelopmental Disabilities

by Joel Schwarz

The new director of LEND (Leadership Education in Neurodevelopmental and Related Disabilities), a major program of the Clinical Training Unit at the Center on Human Development and Disability (CHDD), is out to change the perception that the program “is the best kept secret around here.” Beth Ellen Davis, MD, MPH, a University of Washington associate clinical professor of pediatrics, took over the helm of LEND at the CHDD earlier this year and is planning to increase the number of participants by 50 percent in the next five years as well as expand the program’s geographical reach. Davis is thoroughly familiar with LEND having been a 1999-2000 program participant when she was a trainee while completing a developmental behavioral pediatrics fellowship at Madigan Army Medical Center in Tacoma.

LEND is part of a network of programs supported by the federal Maternal and Child Health Bureau. Each LEND program takes advantage of its unique strengths and builds its training around the needs of its region. The UW LEND has been funded for 45 years and is the centerpiece for clinical hands-on interdisciplinary training at the CHDD and is part of CHDD’s University Center for Excellence in Developmental Disabilities. The program is focused on preparing participants from numerous disciplines for leadership roles in providing a high level of health care and related services for children with neurodevelopmental disabilities, including autism spectrum disorders (ASD).

LEND participants are typically graduate students, post docs and mid-career health professionals who are interested in providing interdisciplinary services to children with a range of disabilities and their families. Medicine and psychology are prominently represented among the LEND trainees, but participants also come from such disciplines as audiology, health administration, nutrition, occupational therapy, physical therapy, social work, special education, and speech and language pathology. A number of parents who have children with neurodevelopmental disabilities recently have added a new dimension to the program with the addition of a parent-professional training track. “We work with anyone dealing with the complex care of children with neurodevelopmental disabilities and we teach them advocacy and ways to build partnerships,” said Davis. “Part of our training is teaching perspectives from other fields that help these children. Our interdisciplinary emphasis provides people with a synergistic approach to solving problems with solutions to complex challenges that exceed what they could derive on their own. I know from my own experiences as a general pediatrician that when parents came to me for help they expected me to have all the answers. LEND taught me to rely on the expertise of other disciplines and to also understand grassroots efforts to help children with neurodevelopmental disabilities.”
Each year, the UW LEND program serves three groups of participants: short-, medium- and long-term trainees. Short-term trainees attend workshops, lectures and other special programs. Davis said people in this group are “too numerous to count.” The second group, which numbers 70 to 80 a year, participates in programs lasting one to several weeks. Long-term trainees, who mostly are graduate students, have a nine-month-long, 300-hour commitment and Davis said it is essentially a one-on-one apprenticeship with a faculty member along with experiences in communities and with their classmates from a variety of fields. Long-term trainees also are required to have a project such as working with a community to build a playground for children with neurodevelopmental disabilities or serving as an advocate in Olympia with state government. The program is designed to teach trainees advocacy and how to build partnerships around the care of children with neurodevelopmental disabilities and related disorders, according to Davis.

Words and phrases such as “invaluable” and “opportunities to improve my leadership skills” are common from graduates of LEND. “One of my favorite aspects was working with an interdisciplinary team where I gained so much knowledge working so closely with other professionals,” said Holly Petaja, Ph.D. and a licensed clinical psychologist. LEND provided Petaja with the opportunity to evaluate a number of children with suspected neurodevelopmental disorders and other problems at the Clinical Training Unit’s Child Development Clinic. “I’ve been able to apply the knowledge and leadership in my private work and am looking forward to continuing this in the future,” she said. Amy Carlsen, RN and the parent of a child with ASD, filled a unique place while she was a trainee by representing the families within LEND. “My training included working within interdisciplinary teams to support family-centered and culturally competent care. LEND has provided me opportunities to strengthen my leadership skills, to better understand the interdisciplinary team approach, and to work with many professionals interested in serving children with special needs and their families. It has also given my family a voice.” One of the assignments that physical therapist Brooke Fitterer had as a trainee was to follow a family as their child was evaluated. “He was assessed by six different specialists and then was given a very unexpected diagnosis of ASD,” Fitterer said. “This kind of opportunity has shifted the direction and focus of my career and I hope to increase my role in the area of advocacy.”

Until this year, LEND participation has been restricted to people who could come to the UW campus, but Davis hopes to change that by the end of the year through a distance learning program with onsite supervisors in Spokane and Yakima. Several students in central and eastern Washington already have expressed interest in the program and this year’s class has distance trainees from Montana and Chehalis, Washington. There is no shortage in the need for trained professionals to work with children who have neurodevelopmental disabilities and improve the care available to them.

A program such as LEND is needed because “children with neurodevelopmental disabilities have significant challenges and big needs over their life-span,” said Davis. “As a society we have a poor history of helping them. LEND is building a regional and national cadre of interdisciplinary providers who understand the power of team advocacy and support. LEND is not designed to just protect, but also to help children with neurodevelopmental disabilities reach their potential. Anyone who is considering a career in some aspect of neurodevelopmental disability care should consider being a LEND trainee. I don’t know how you could be completely successful without knowing how to collaborate with other professionals to serve children with special needs and their families.”