Interdisciplinary Professional Training in Developmental Disabilities: An Update

by Kate Forster

When a family first receives news confirming that their child has a developmental disability, they enter a world where the challenges can seem insurmountable. While raising any child is hard, raising a child with a developmental disability brings a host of new challenges and complications. A diagnosis such as autism spectrum disorder (ASD), for example, affects every aspect of a family’s life—from education, childcare, and transportation, to areas that may not be immediately apparent, such as nutrition and parental self-care. “Developmental disabilities, because of their complex nature, require an interdisciplinary approach,” said Ellen Davis, MD, MPH, clinical professor of pediatrics, and director of the UW LEND program at the Center on Human Development and Disability (CHDD). “This is why professional training programs that take an interdisciplinary approach to diagnosis of developmental disabilities, such as that offered by LEND, are so valuable.”

LEND stands for Leadership Education in Neurodevelopmental and Related Disabilities, and it is part of a network of programs supported by the federal Maternal and Child Health Bureau. The UW LEND has been funded for over 45 years and is the centerpiece for clinical hands-on interdisciplinary training at the CHDD. It is part of CHDD’s University Center for Excellence in Developmental Disabilities. The program is focused on preparing trainees, known as fellows, from numerous disciplines for leadership roles in health care and related services for children with neurodevelopmental disabilities, including ASD. A unique feature of this program is a diagnostic center which provides fellows with the opportunity to observe and practice in a true interdisciplinary family-centered clinic and gain hands-on experience.

Interdisciplinary diagnostic clinic

Participants in the program come from a variety of disciplines. The fellows are comprised primarily of post-graduate students completing their work in such disciplines as audiology, occupational therapy, speech-language pathology, physical therapy, developmental behavioral pediatrics, nursing, social work, psychiatry, and psychology. Training is also provided to practicing health professionals who are interested in expanding their knowledge and skills in providing services to children with developmental disabilities and their families, and a new parent-professional training track provides training to parents who have children with neurodevelopmental disabilities. The trainees gain a wealth of knowledge, experience, and expertise as they participate in an interdisciplinary diagnostic team, where they learn to rely on the capabilities of other disciplines and to appreciate the interdisciplinary approach to helping children with neurodevelopmental disabilities and their families. The LEND’s interdisciplinary team approach is well-suited for seeing children with significant
psychological and neurological complexity, and this has gained it a reputation among other diagnostic centers. When other providers are stumped or feel overwhelmed, they will often refer a family to the Child Development Clinic supported by the interdisciplinary faculty and fellows of the LEND program.

Recent updates to LEND

The recently added Family Leadership Discipline includes two fellows who are already leaders in their communities. Sue Adelman is an occupational therapist, and Joel Domingo is an educator. Each has a child with a developmental disability. Not only do they provide professional expertise, but they also bring the unique perspective of the parent to the clinical setting. This is especially valuable as they counsel the diagnostic team on how to deliver a diagnosis to a family. Amy Carlsen, RN, heads the Family Leadership Discipline. As a former trainee, nurse, and parent of a child with special needs, Carlsen fills a unique role as a LEND faculty member. “Being in the LEND program—first as a trainee and now as a faculty member—is my way of having a voice and making an impact,” said Carlsen, “I understand the professional provider world and the parent world, and I help both worlds understand each other.”

New autism services for families

The unique connection with the community that the UW LEND has established with its diagnostic clinic paved the way for the Parent Autism Support Service (PASS) program, which is offered through the Family Leadership Discipline. The PASS program offers continued support for parents for six months after receiving a diagnosis of ASD or another neurodevelopmental disability. One example of a parent who benefitted from the PASS program is Tramy Nguyen, whose two sons were both diagnosed with ASD. Because Nguyen is a non-native speaker of English, fellows and faculty from the PASS program worked with her school district to ensure that her boys were given the special services they needed to succeed in school and that there was no miscommunication. Not only did Nguyen find others who understood what she was going through, but she learned of resources available to her and her family that she wouldn’t have otherwise been aware of. Nguyen found the resources at LEND invaluable. “They gave me so much hope in an overwhelming situation,” she said.

Extending LEND’s influence

Since Davis began as LEND director four years ago, she has increased the number of participants in the UW LEND program by more than 50 percent, including the number of participants from the community. In 2015, Davis expanded the program’s geographical reach to include a satellite LEND program in Yakima, WA, which includes a clinic, a faculty member, and three trainees. “This has opened the door for us to get involved with rural health work that we would have never had access to from Seattle,” she said. Davis also added a self-advocate training position, which she feels has strengthened the experience for all participants in the program. “Addressing the needs of individuals who are represented in the learning process makes the training experience really credible. Having a self-advocate fellow has also helped us prioritize advocacy skills. We decided that we wanted our trainees to leave this program knowing how to contact their legislators, look up a bill, talk to a policy maker, and advocate for individuals and families who have a developmental disability. I am confident our trainees leave with these skills that they can apply whenever their experiences allow them to.”