



UW LEND – Training the Next Generation of Leaders in ASD

by Kate Forster

As autism spectrum disorder (ASD) becomes the fastest growing developmental disability in the United States, with a diagnosis rate of 1 in 68 individuals, there is a growing need for quality training programs to help prepare the next generation of professionals to support children and families with this heterogeneous and complex neurodevelopmental disorder. The LEND training program at CHDD is among those at the forefront. 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 and based at the CHDD's University Center for Excellence in Developmental Disabilities. It is a hands-on, interdisciplinary training program that prepares professionals for leadership roles in the field of ASD and related developmental disabilities. One third of LEND graduates go on to work primarily in the field of autism, many achieving leadership positions.



Sally Stuart is the interdisciplinary training director for the UW LEND program, where she plans and implements leadership training at the CHDD.

Sally Stuart, Ph.D., LICSW, is the interdisciplinary training director for LEND, where she is responsible for planning and implementing interdisciplinary leadership training for all the trainees. "Because a diagnosis of autism affects all aspects of a family's life, not just one or two, it's important for our trainees to understand how they as well as other disciplines can help meet the needs of the family," she said. Most LEND trainees are doctoral or post-doctoral students who come from a variety of disciplines, while other trainees are mid-career professionals in the community; a few are parents caring for a child with a neurodevelopmental disability. The participants come from such disciplines as psychology, pediatrics, social work, nursing, physical or occupational therapy, speech-language pathology, audiology, and nutrition, among others, and each is assigned a faculty mentor who is a leader in their particular field. "The interdisciplinary nature of our program involves teaching perspectives from all of the different fields that support children with ASD and their families. This is essential so when our graduates go out and become members of the community, they can all be on the same page, and they can all know what resources are available and not get siloed within their particular field. This way, families get the same messages from different practitioners," she said.

Leadership education is woven into LEND's interdisciplinary curriculum, which contains didactic instruction, clinical practice, and community experience. The weekly didactic core seminars bring in speakers from a variety of health and related disciplines at the University of Washington as well as other institutions, and they have included such diverse topics as Ethics in Autism, ASD and Nutrition, and Genetics of Autism. Trainees get their mentored clinical practice at the on-site Child Development Clinic,

where they participate in an interdisciplinary team and regularly meet to evaluate and diagnose individuals who come into the clinic.

LEND trainees are also mentored to assume leadership roles in the community as part of their community involvement requirement. This can range from participating in committees, such as the Washington Autism Advisory Council, to becoming involved in the Community Asset Mapping program, which implements more autism services to some of the underserved communities in Washington State. The Community Asset Mapping program is a collaboration among LEND, the Washington State Department of Health, and the Medical Home Partnerships Project.

As a supplement to this curriculum, LEND trainees are expected to develop an annual leadership project that they present at the end of the academic year. The project corresponds to their field of study and professional goals, and it often emphasizes new research in intellectual and developmental disabilities (IDD) or explores new intervention strategies for children and families.

LEND helps former and current trainees become leaders in the community

One recent LEND graduate who has successfully extended his leadership project into the community is Ben Aaronson, Ed.S. Aaronson is the director of the CHDD Autism Center's Apex Summer Camp, a five-week summer camp designed for youngsters diagnosed with ASD. As a LEND trainee, Aaronson's leadership project involved launching the camp. "I wanted to create a camp that was meant to provide a safe social space for kids with autism, as well as a space where they could build social and behavioral skills," he said. "It's a real-world summer camp environment that kids can use as a training ground for building skills that they can't really build in a clinic." Aaronson credits his LEND training with helping inform the model he created for the camp. "As a result of my experience at LEND, I feel better prepared to encounter the variety of challenges that the families we serve face," he said.



The Arc of Washington State

Ivanova Smith, who has ASD, is the first-ever UW LEND trainee focusing on self-advocacy. After she graduates, she will become a faculty member in the UW LEND program.

Ivanova Smith is another LEND trainee who is effecting change in the ASD community. Smith is the first-ever LEND fellow in the program's advocacy discipline, and she is an individual with ASD. Her passion for disability rights activism brought her to LEND, and her involvement in the program has allowed her to engage as a leader in the ASD advocacy community. As a LEND fellow, Smith helped create the Pierce County chapter of the ASD advocacy organization, People First, and she became that chapter's first president. She also became co-chair of Self Advocates in Leadership, a Washington State coalition of individuals with IDD who work to shape the public policies that affect their community.

"I've been able to do a lot of public speaking as part of my LEND fellowship, both here at LEND and in the community, where I do a lot of civil rights activism," said Smith. "This training is helping me develop important leadership skills so that I can give my voice to others." Smith recently gave the keynote address at the annual luncheon for The Arc of King County, a nonprofit organization serving individuals with IDD and their families. Once Smith graduates, she will become the first LEND faculty member with ASD, where she hopes to mentor future trainees with ASD in self-advocacy.

CHDD is an interdisciplinary center dedicated to the prevention and amelioration of developmental disabilities through research, training, clinical service, and community outreach. CHDD includes the University Center of Excellence in Developmental Disabilities and the Eunice Kennedy Shriver Intellectual and Developmental Disabilities Research Center.

CHDD Outlook

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