

## Illinois LEND FAST Project Summary and Lessons Learned (February 2018)

### Background

Across the state, Illinois LEND (IL LEND) strives to build clinical capacity through academic and community partnerships. However, despite our program's statewide efforts, Central Illinois (IL), which is predominantly rural, remains an underserved region for ASD services and supports partly because of the shortage of developmental pediatricians in the area. About a third of Illinois children reside outside of the metropolitan Chicago area and many rural families travel to neighboring states (e.g., Missouri) in order to obtain necessary health and therapeutic services. In order to increase clinical capacity for ASD services and supports in the region, we need to leverage and to strengthen the expertise of the existing workforce, particularly rural primary care professionals.

Due to the shortage of developmental pediatricians in rural Illinois, diagnoses of ASD are increasingly being provided by non-medical specialists, such as clinical psychologists. This strategy is a cost-effective way to provide ASD diagnoses to rural families who, otherwise, would not be able to access this critical service necessary to access evidence-based interventions. Yet, children with ASD still have medical issues that need to be addressed by a primary care professional with familiarity and expertise with ASD. Through the planning grant, we propose to develop training model for rural primary care professionals and residents to help them become more competent and comfortable to provide medical and family supports that are commonly needed among families with newly diagnosed children with ASD.

### Needs Assessment

We conducted listening sessions with resident physicians in Central IL. Through these sessions, we learned that residents have knowledge gaps related to early identification, available standardized tools, genetic testing and family support. Residents also preferred self-paced modules as a mode of training.

We planned to conduct similar listening sessions with practicing primary care physicians in the area who would receive a stipend for participation. Scheduling of these sessions proved to be problematic even if offered at various times during the day or even in conjunction with an already scheduled lunch meeting. Time was a greater barrier to physician participation and was not alleviated by the stipend. Therefore, we changed strategies and opted to conduct an online needs assessment instead. This survey was adapted from an online survey from Colorado LEND and was disseminated through to family medicine physicians throughout the area via Illinois chapter of American Association of Family Physicians and via Southern Illinois School of Medicine's training sites. Through the survey, we learned that physicians wanted to know more about family support and community resources and would like to also learn via self-paced modules.

### Module

Because there are many existing curricula and resources about early identification and medical comorbidities (i.e. CDC Know the signs/ Act Early), we decided to focus on a family support module specific to the resources and system navigation in Central IL. The

module was created with input and expertise from the stakeholder groups and identified local resources in the area. Topics included: early intervention, special education, day care, respite, Medicaid waivers. After reviewing available options, Camtasia was chosen as the software that would be used to create the interactive module.

Initial pilots of the module were well reviewed, but we but found significant challenges of identifying and maintaining a host platform for the training that was accessible to all partners. Additionally, our downstate partners were interested in using their own resources to discuss family support with physicians-in-training and wanted to be easily able to update information. In 2016, the Illinois Action for Children (a child care assistance program) developed a [series of easily accessible videos](#) that covered many of the topics in our proposed family support course. We use these videos to as part of our LEND didactic material and are working to get them included in residency training programs in Chicago and Central IL.

### Central Illinois Partnership

In order to enhance early identification of children with ASD and to expand knowledge of health related services and family supports, we implemented an ongoing partnership between IL LEND, community providers, Central IL rural primary care professionals and residency training programs. This group, which included IL LEND trainees, met monthly throughout the duration of the award.

The impact and benefits of this partnership extended beyond the award period and resulted in incredible gains for our LEND program and for capacity building in Central IL. Our partnership allowed IL LEND to add a training site in Central IL, which is a partnership between two academic centers and one community partner (an Easter Seals therapeutic program in Peoria). IL LEND recruited Dr. Janet Patterson, Central IL developmental pediatrician, to be IL LEND faculty and assisted with her successful application to be a CDC Act Early Ambassador. In this role, Dr. Patterson provides targeted technical assistance to rural providers about ASD diagnostic process and family supports. We have continued to add faculty at new Central IL LEND training site. At this point, four of our LEND faculty (Dr. Patterson, a special educator, a nutritionist and a social worker) are in Central IL. In 2018, we expect to recruit another faculty member, a psychologist who is also the director of an autism diagnostic center in Champaign, IL, which has served as a clinical site for our trainees in that area. We have also tripled our trainees from the region. Many of these trainees plan to remain in Central IL, which will build the workforce to care for individuals with autism and other neurodevelopmental disabilities.

Moreover, in collaboration with our key stakeholders, medical professionals, and Central IL LEND faculty, we coordinated our first LEND autism screening event in Champaign, IL in early November, 2017. We have had community screening events in underserved areas of Chicago area the past five years. Through these events, LEND trainees have an opportunity to practice communication with families and ASD screening under the supervision of LEND faculty. Local families benefit from system navigation and individual technical assistance. Our screening event in Champaign was the most widely attended screening of this academic year, reflecting the need for ASD identification and diagnostic services in that area. The FAST project also led to the formation of an interdisciplinary group (including two of our LEND faculty and a primary care physician) that is continuing



to meet to discuss ways to improve services for families and individuals impacted by ASD. This group is currently collaborating on improving how the main clinic in the Central IL (Carle) delivers services for youth with ASD.

We remain aware of the need for further physician training in this community. We anticipate that our opportunities to support this training will increase as we continue to expand our LEND program in Central IL. Having local providers who are involved in LEND provides credibility for our continued outreach and also provides a platform for continuity.