



Building Clinical Capacity about ASD and other Neurodevelopmental Disabilities among Rural Providers

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RESEARCH, EDUCATION, SERVICE

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Session Overview

- (1) Provide background on the screening, diagnosis, access to care, and support challenges experienced by children with ASD / NDD and their families in rural communities
- (2) Highlight two projects that addressed rural workforce capacity issues in innovative ways
- (3) Discuss lessons learned, promising practices, and opportunities to advance the broader network



Why is this a Priority?

Screening instruments may not be as valid and reliable

- Scarpa et al. (2013): M-CHAT was not reliable among low-income and ethnic minority families in rural areas

Lower diagnosis rates

- Dickerson et al. (2016): Data from CDC ADDM Network found lower prevalence rates in rural areas compared to urban areas

When diagnoses occur, they are later in rural areas

- Mandell et al. (2005): On average, diagnoses in rural areas occurred five months later than in urban areas; diagnoses from children from near-poverty levels occurred on average 11 months later than children from 100% above poverty levels
- Kalkbrenner et al. (2011): Diagnoses occurred 3-16 months later in Health Professional Shortage Areas than in areas with higher density of physicians and psychologists or areas in close proximity to a medical school
- Rhoades et al. (2007): Trends showed that more parents from rural and mixed (rural/urban) areas reported not receiving additional information regarding their child's diagnosis from a provider when compared to parents from urban areas



Why is this a Priority?

Lack of availability of primary and specialty care

- Mandell et al. (2010): Counties with greater numbers of pediatricians and pediatric specialists per capita had a higher proportion of Medicaid-enrolled children with ASD

Family supports are not accessible

- Mandell & Salzer (2007): Parents of children with ASD from rural areas were less likely to participate in support groups than suburban parents; support group participation was greater for families that were referred by their primary care provider





Example: Colorado

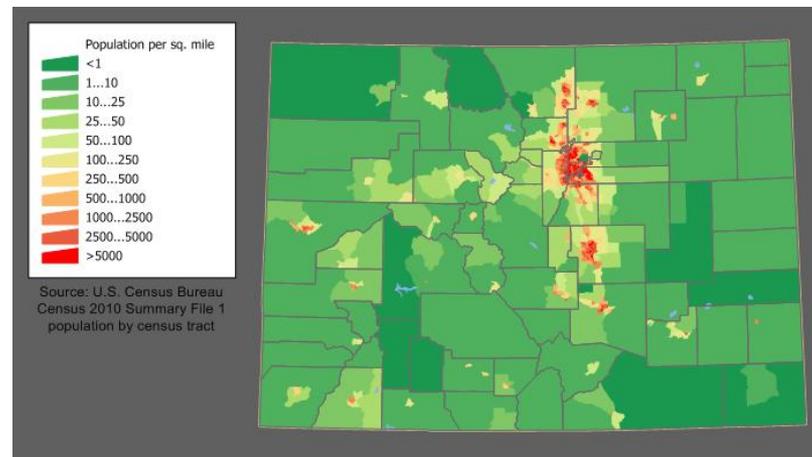
Sparsely populated state; 37th nationally in population density

One-third has “frontier” designation (i.e. < 6 people per square mile)

Bisected by the Front Range of the Rocky Mountains; 70% of residents live in a North-South urban corridor along the eastern edge

48 counties (75%) are entirely or substantially Medically Underserved Areas

22 counties (34%) are Health Professional Shortage Areas for primary care, as are 56 counties (88%) for mental health





Focused Assistance to Support Training (FAST) Projects

Funded through a cooperative agreement between AUCD and HRSA's Maternal and Child Health Bureau

Eligible programs submitted proposals for brief, low-cost (up to \$10,000) projects to build capacity in one priority area

Selected programs based on:

- Alignment of needs, goals, objectives, and activities
- Potential program (i.e. training), community, and network impact
- Measurement and sustainability

Submit multiple progress reports and disseminate findings, products, etc.

Receive ongoing technical assistance from AUCD, MCHB, and other programs (e.g. peer-to-peer conference calls)

DBP Connections: Engaging PCP in Case Consultation via Telehealth in Rural Colorado

Sandra Friedman, MD, MPH
Paul Dressler, MD
Susan Hepburn, PhD

Impetus

- ▶ Prior quantitative and qualitative needs assessment indicated that PCPs wanted more collaborative and direct interactions with developmental pediatricians about assessment and management of children with ASD/DD
- ▶ Wanted to support PCPs to:
 - Manage more children in their practice, and thus potentially refer less frequently for specialty care
 - Improve medical/behavioral health care for children with ASD/DD

Impetus

- ▶ Project ECHO:
 - Initiated in Fall 2014 to support PCPs in the management of children with ASD/DD
 - HIPAA compliant case-based presentations in which PCPs participate via videoconferencing to discuss clinical issues and problems to aid in management within their primary care practice

Impetus

- ▶ Long process of preparation
 - Advertising
 - Working with physician relations
 - Obtaining CME
 - Support from hospital Telehealth group
 - Finding “right” day/time
 - Improving format: MD (attending, fellow), psychologist (2nd year fellow), social worker, and guest panelists (OT, SLP, etc.)
- ▶ PCP who participated provided positive reviews
- ▶ PCP participation limited despite efforts

Project Goal

- ▶ Explore perspectives of PCPs regarding telehealth delivery of didactics and case consultation using ECHO model

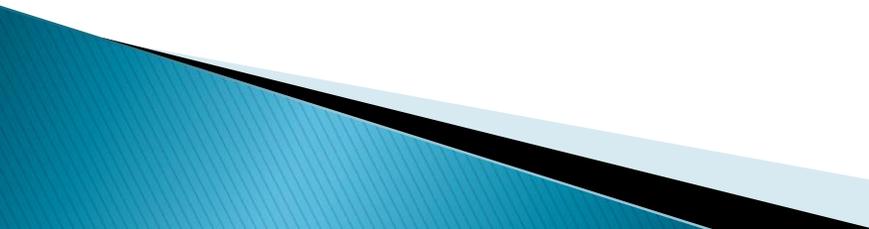
Process

- ▶ ITAC funding to evaluate barriers to PCP participation
- ▶ Project:
 - Worked with family member with strong community connections
 - LEND/DBP fellow took ownership of project
 - Used as a community outreach activity and capstone project for MPH degree

Process

- ▶ Reached providers across state
 - CO has rural and frontier areas that are lacking in specialty providers
- ▶ Visited practices
 - Brought lunch
 - Provided presentation on Project ECHO
 - Asked for feedback about desirability, usefulness, timing, and specific needs of their practices

Outcomes

- ▶ Generally positive comments during meetings with PCPs
 - ▶ Some differences in desired day/time for telehealth conferences
 - ▶ Some practices unaware of program, despite outreach efforts
 - ▶ Varying attitudes regarding referrals and their perceptions of self-efficacy
 - ▶ Despite report that they would participate, there was no increase in participation from these groups after our meetings
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Barriers

- ▶ Problems scheduling lunchtime meetings
 - ▶ Difficult to find appropriate practice contacts
 - ▶ Time constraints of PCPs
 - ▶ PCPs do not have much control of own schedule
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Lessons Learned

- ▶ PCPs may indicate desire for more opportunities to directly interact with specialty providers, yet their schedules do not lend themselves to be able to do so
 - ▶ CME at no cost is not a good motivator for MD participation
 - ▶ We may need to direct our presentations into smaller modules, rather than ongoing, twice monthly events
 - ▶ Consider asynchronous types of presentations
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Training Implications

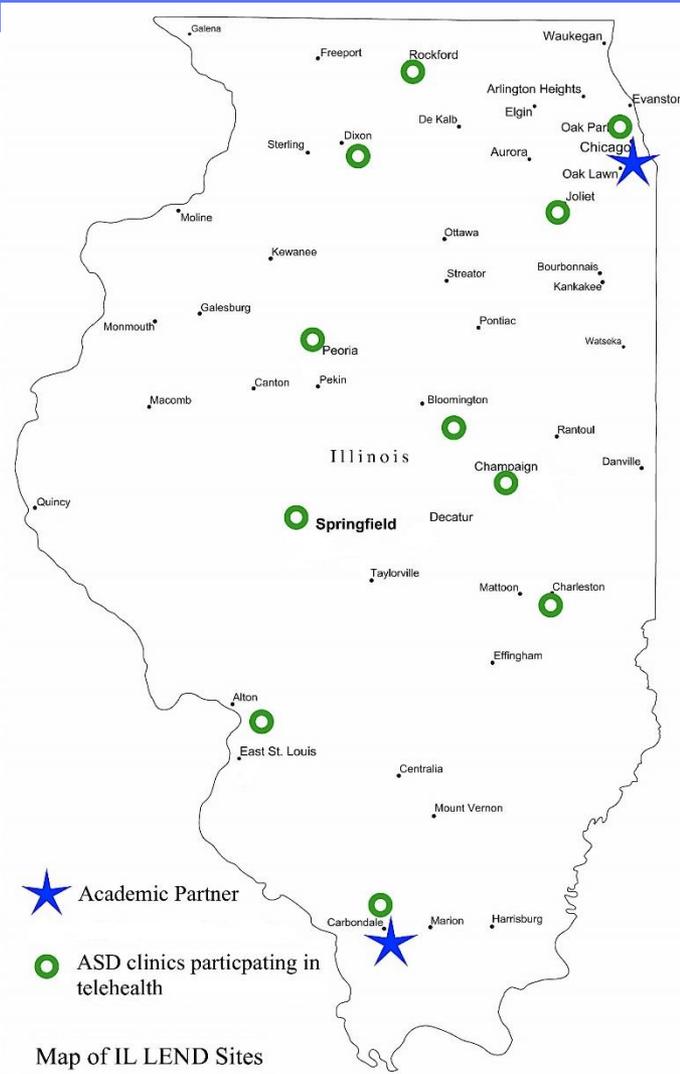
- ▶ Good experience for fellows, who learned:
 - Leadership skills in project initiation and implementation
 - How to set up and evaluate a program
 - Some logistical aspects of telemedicine
 - To interact with physician relations
 - Ways to work continuing education office
 - How to develop advertising materials
 - Content information for presentations
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Engaging Rural Healthcare Professionals in ASD Identification and Family Support



Kruti Acharya, MD
IL LEND Director

Why is this a Priority?



Engaging Rural Healthcare Professionals in ASD Identification Project

- Main goal:
 - ▣ Develop a sustainable model of training for primary healthcare professionals and resident physicians in Central Illinois that meets their needs and helps them to improve earlier identification of children with ASD, address related medical issues, and support families

Goals and Objectives

- **Goal 1:** Determine the knowledge gaps of rural primary health care professionals and of resident physicians and to understand the barriers faced to care regarding ASD identification, related health needs, and family supports

Goals and Objectives (cont.)

- **Goal 2:** Implement an ongoing partnership between IL LEND, community providers, Central Illinois rural primary care professionals, and residency training programs, in order to enhance early identification of children with ASD, as well as provide health related services and family supports

Goals and Objectives (cont.)

- **Goal 3:** Create a model of in-service training about ASD identification, medical supports, and family supports targeting rural primary healthcare professionals and primary care resident physicians
- **Goal 4:** Develop a plan to disseminate and sustain the in-service training in Central IL for both practicing rural primary care and resident physicians

Activities and Outcomes

- **Goal 1: Identification of knowledge gaps**
 - Listening sessions attempted, but scheduling difficulties
 - Surveys
 - Residents identified knowledge gaps in early identification, referral for treatment, medical home management, and family support
 - Practicing physicians reported knowledge gaps related to family support
 - Residents prefer self-paced modules for training, whereas practicing physicians prefer targeted technical assistance about specific cases

Activities and Outcomes (cont.)

- **Goal 2: Partnership development**
 - Monthly stakeholder working group meetings
 - Outcomes:
 - IL LEND opened a new training site in Central IL in conjunction with grant partners
 - IL LEND supported Dr. Patterson, Central IL pediatrician, in her successful application to be a CDC Act Early Ambassador

Activities and Outcomes (cont.)

- **Goal 3: Development of model of in-service training**
 - Survey data analysis; ASD training and resource development
 - Outcomes:
 - Resident curricula designed using existing evidence-based modules and new family support module
 - Family support module ready to pilot test with residents and practicing physicians
 - Planning for ECHO ASD in Spring 2017

Activities and Outcomes (cont.)

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COMMUNITY SUPPORTS FOR YOUR PEOPLE WITH DISABILITIES (PWD)

Dr: What to do until the social worker comes ?

illinois LEND

Next slide

Where and Why to Refer for Community Services

- Non-medical services are key to good outcomes
- Families have regular contact with their primary care providers and may not learn of these services from anyone else in a timely manner
- You can make a big difference simply by providing contact info to a key service
 - It's not up to you to be sure someone is actually eligible, the agency referred to will do that

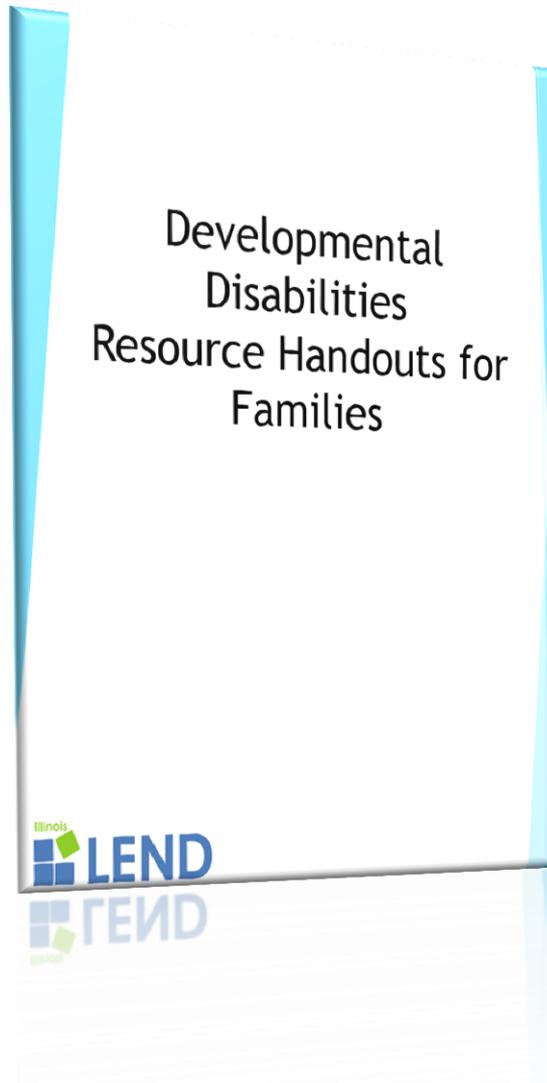
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No Notes.

Slide 1 of 27

Family
Support
Module

Activities and Outcomes (cont.)



Family Support Directory

Activities and Outcomes (cont.)

- **Goal 4: Dissemination and sustainability**
 - Meetings with residency program directors, publicity through social media and partner websites, and targeted mailing ongoing
 - Outcomes:
 - Janet Patterson, Act Early Ambassador, joined IL LEND faculty in August 2016 to offer targeted TA to rural office practices
 - New LEND training in Central IL sustains training locally

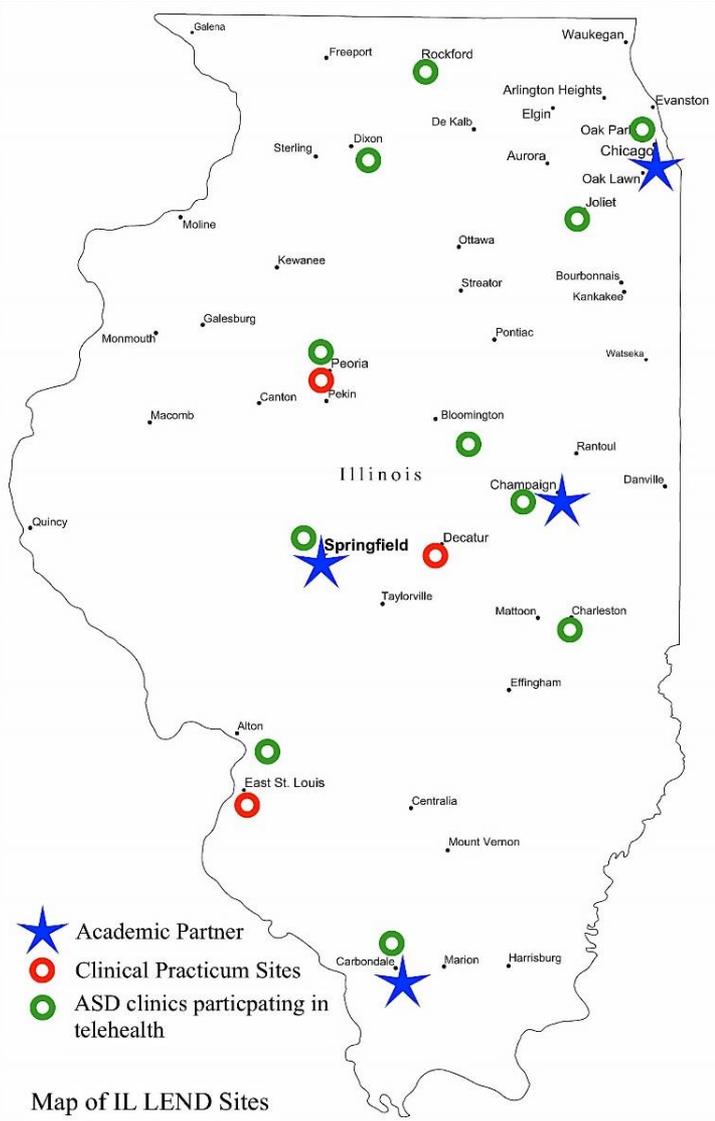
Challenges

- Physician availability to participate in the listening sessions
- Buy-in and dedicated time from community-based professionals
- Selecting appropriate delivery mechanisms for training content

Benefits

- Project has facilitated the development of a robust sustainable collaboration with partners in Central IL
- Trainee engagement
- The family support module developed as a result of this award will fill a training gap for Central IL resident and practicing physicians

Benefits (cont.)



Plan for Sustainability

- Family support module will be embedded into existing resident training
- Family support module will be updated at minimum every two years
- A digital and hard copy directory of family support information is being created to be used as a quick reference by practicing physicians that have limited time
- Project ECHO ASD being planned for Central IL

Lessons Learned

- Time is a primary barrier to engagement of practicing physicians; similar programs should limit the time burden of participation
- The delivery method of training content should be responsive to the educational needs and preferences of front-line medical professionals



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