

## LEND and Learn TA Series

# Title V collaboration and partnership opportunities for LEND programs

Wednesday, September 20, 2023

3:00 PM-4:00 PM



INTERDISCIPLINARY TECHNICAL ASSISTANCE CENTER  
ON AUTISM AND DEVELOPMENTAL DISABILITIES

- Ensure your name is displayed correctly in the participant list. You may also include the program name and state and preferred pronouns.
  - Example: Jeanette Cordova, AUCD, she/her
  - Hover over your name in the “Participants” box and select “More” → “Rename”
- Remain muted unless speaking
- State your name prior to speaking
- Captioning is available
- Recording is only available for attendees and upon request
- Use the chat box to introduce yourself!
  - Name, Role, Program
  - If you had an extra hour in your day, how would you spend it?



# LEND and Learn TA Series

- 4th Monday of the month at 3 PM ET
  - May change due to availability of LEND program and/or holidays
- Opportunity for LEND leadership and faculty to discuss priority TA topics and to learn from each other
- Led by a different LEND program each month (15-minute presentation, followed by open conversation)

- **Monday, October 23, 2023 at 3:00 PM ET**
  - Disability Badge Program
  - Led by WVU LEND
  
- **Monday, December 4, 2023 at 3:00 PM ET**
  - Operationalizing the Self-Advocacy Discipline Competencies
  - Led by Rochester LEND



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# Title V collaboration and partnership opportunities for LEND programs

**Wednesday, September 20, 2023**

*Presented by:*

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Associate Director, Child Health and Children & Youth with Special Health Care Needs  
(& Proud WI-LEND graduate!)



ASSOCIATION OF MATERNAL & CHILD HEALTH PROGRAMS

# Session Objectives

## **This session will provide:**

- A crosswalk of shared priorities across LEND, DBP, and Title V programs,
- An overview of Title V opportunities for LEND programs and their trainees,
- Examples of existing LEND/Title V partnerships, and
- An opportunity for LEND/DBP programs to discuss and ask questions.

# Level setting: What is Title V?

## The MCH Services Block Grant (Title V of the Social Security Act of 1935):

The nation's longest standing public health legislation focused solely on improving the health of all mothers and children, including children with special health care needs (*CSHCN*)

## Appropriates funds to states to:

- Ensure access to quality health services
- Promote the health of children by providing preventive and primary care services
- Provide and promote family-centered, community-based, coordinated care for children with special health care needs

➤ Only **THREE** Title V CYSHCN Programs are co-located at Universities (Illinois, Iowa, and Oregon) that also implement the LEND program.



# Overlapping Priorities

## Title V

- Partnerships with individuals/families/family-led organizations to ensure systems and services that support the interests of all MCH populations.
- Provide training, both in orientation and ongoing professional development, for program staff, family leaders, volunteers, contractors and subcontractors in the areas of unconscious bias and cultural/linguistic competence.

## LEND

- Provide technical assistance to local, state, and national programs and agencies to improve the system of care for people with disabilities.
- Enhance family participation at all levels of program design, implementation, and evaluation.
- Promote innovative practice models that enhance cultural/linguistic responsiveness, partnerships among disciplines, and person-/family-centered approaches to care.

## DBP

- Opportunities to coordinate with Title V systems of care, including developmental screening initiatives.
- Coordinate clinical training opportunities with HRSA-funded research sites and Title V programs.

# Articulating the Need for Stronger, Meaningful Collaborations

- From LEND NOFO: State Title V agencies and state and local home visiting implementing agencies may provide opportunities for LEND programs to collaborate, thereby enhancing and expanding services for children with neurodevelopmental disabilities and special health care needs.
- Both LEND and DBP programs are required to provide technical assistance to and work collaboratively with community agencies and other MCH stakeholders, including Title V agencies to maximize access to MCH services, with emphasis on ASD/DD.
- **Not so fun facts:**
  - Only 24 states mention their collaborations with LEND programs in their most recent Title V Block Grant reports.
  - Title V programs in states with a DBP training program did not mention any collaborations with DBP programs in their most recent Title V Block Grant reports.
  - LEND Directors have stated challenges in creating comprehensive practicum experiences for non-clinical trainees, especially family and self-advocate trainees.



# Alignment of Title V Program Needs with LEND Program Requirements

# NEED: Developmental Screening

- Title V has a National Performance Measure related to increasing parent-completed developmental screenings (38 states have currently selected this as a priority).
- Aligned with LEND program requirement to address gaps in the systems of care for individuals with ASD/DD, specifically through training clinical and community providers to screen for ASD/DD.
- Clinical and Non-Clinical trainees can conduct clinic and community-based screenings to increase rates of developmental screenings (national average is currently less than 40%).

# PARTNERSHIP EXAMPLES: Developmental Screening

## Alabama Title V CYSHCN partnership with Early Intervention (EI), the University of Alabama, and the UAB Civitan-Sparks Clinic

- Developed a pilot Pediatric Evaluation – Autism Diagnostic Clinic in the Tuscaloosa office for children currently enrolled in EI. Children will be identified by EI to participate, screened for enrollment into the CYSHCN program, and subsequently scheduled for the diagnostic clinic

## NH-ME community outreach efforts to increase developmental screenings

- NH-ME LEND trainee leadership placements will conduct outreach efforts to child health providers on the use of Learn the Signs Act Early materials in practices throughout NH, and the implementation of a Developmental Screening Event project plan based on the Help Me Grow “Books, Blocks and Balls” parent engagement events.

## Oklahoma Title V Partnership to increase outreach to underserved communities

- Title V Family Partner will engage in the planning of a new Mobile Autism Clinic being developed by the JumpStart Team and Oklahoma LEND program designed to increase outreach to Oklahoma families in underserved communities.

# NEED: Epidemiology Support

- Title V programs report major capacity issues in their epidemiology programs. This impacts data collection and the ability of the Title V program to provide accurate data to inform activities and be able to share results of the Needs Assessment with the public.
- Aligned with LEND research, evaluation, and/or quality improvement activities.
- Comprehensive needs assessment and coordination of efforts across MCH-related programs are influenced, in part, by the state's ability to collect, access, link, and analyze timely data across multiple systems and programs (e.g., vital records, child health surveys, MCH Jurisdictional Survey, newborn screening, Medicaid claims, immunization and birth defects registries, hospital discharges and WIC).

# PARTNERSHIP EXAMPLE: Epidemiology Support

## Kansas Title V Program + LEND Collaboration

- LEND trainee assisted with a systems of care project designed as the first step to:
  - Creating a shared dataset (list of measures, metrics, or information shared across public and private health systems to determine if systems of care are “well-functioning”);
  - Telling the story of what systems look like for the CSHCN population – in Kansas;
  - Establishing a model of partnership to support cross-system data sharing practices to enhance systems of care; and
  - Providing a pathway for patient-level data sharing among public and private health systems to improve access to continuous, comprehensive, and coordinated care.

# NEED: 5-Year Needs Assessment

- Title V programs typically begin their Needs Assessments roughly 2 years prior to the start of the next 5-year cycle.
  - They also must provide annual updates on ongoing Needs Assessment Activities with each annual report.
- This Needs Assessment includes a comprehensive review of MCH population needs, program capacity, and partnerships/collaborations that are critical components of a state's system of care for addressing the needs of its MCH population.
- Aligned with LEND research, evaluation, and/or quality improvement activities.
- **Why does this matter?** Title V programs must engage stakeholders in this process to solicit meaningful programmatic input. Title V programs can use a lot of support with this, especially as it relates to engaging historically marginalized populations and ensuring any unique needs are accounted for in the Assessment.



# PARTNERSHIP EXAMPLE: 5-Year Needs Assessment

## Alabama

- UAB School of Public Health's Applied Evaluation & Assessment Collaborative (AEAC) administers and analyzes statewide surveys to assess the system capacity to address the needs of CYSHCN.
- The UAB AEAC also administers the CYSHCN program's Transition survey to assess the percent of youth with SHCN who report satisfaction with their transition experience to adulthood.

## Oregon Community Broker model

- Oregon CYSHCN program staff served as a research mentor to a LEND trainee, which led to an innovative culturally-responsive community needs assessment to understand the needs of families and young adults with special health care needs who are members of Black and Latino communities.
- This project contributed vital information that the Oregon Title V CYSHCN program had never been able to collect, by utilizing a community-broker model of collecting information from historically marginalized communities.

# NEED: Increasing paid Title V staff with lived experience/expertise

- Family Partnership section of the Title V Block Grant: *“Family engagement reflects a belief in the value of the family leadership at all levels from an individual, community and policy level”*.
- States are also prompted to identify a State Family or Youth Leader
- Aligned with LEND program inclusion of families and self-advocates as members of interdisciplinary teams.
- **Why does this matter?** Title V programs are strongly recommended to have **\*PAID\*** Family Leaders on staff to contribute to program processes, such as assessment of needs/assets, program planning, MCH and CSHCN services delivery, and evaluation/monitoring/quality improvement activities.

# PARTNERSHIP EXAMPLE: Family/Self-Advocates as Title V staff

## LEND to Title V Workforce Pipeline: Alaska

- Alaska Title V seeks and values parent and consumer feedback on all programs and recruits parents, providers, youth, and communities to help set priorities and initiative activities at all levels.
- To operationalize this, they have a formal role of Family Engagement Lead as a Title V staff members, which is currently held by a former Alaska LEND fellow.

## Tennessee Youth Advisory Council

- Tennessee Title V collaborated with the LEND program to create its Youth Advisory Council.
- LEND trainees are engaged to assist with planning and facilitating meetings.



# Discussion

# FORTHCOMING RESOURCES

- Revamped e-Learning Modules
  - The Autism CARES Act 101 (Available now!)
  - The History of Title V Children & Youth with Special Health Care Needs Programs
- We invite you to sign up for our SPHARC newsletter via our website homepage
- Let us know how we can support you via our inbox: [SPHARC@amchp.org](mailto:SPHARC@amchp.org)



# Thank You!

*Please share feedback on today's sessions and ideas for  
future LEND and Learn sessions*



<https://www.surveymonkey.com/r/LENDTASession4>

**Full Team Email: [itac@aucd.org](mailto:itac@aucd.org)**