The MCHB-funded Leadership Education in Neurodevelopmental Disabilities (LEND) Programs from the Great Lakes LEND Collaborative present:

Genetics, Ethics, & Disability

Thursday, October 9th
7:45am-12noon
University of Illinois at Chicago, College of Nursing
Third Floor Event Center, Chicago, IL

Participants in the morning session will be able to:

- Learn more about the range of ethical issues related to disability and genetics from the perspectives of providers, researchers, parents, and advocates.
- Describe how genetic technologies may affect the decision-making process of families and individuals with developmental disabilities, including autism spectrum disorders.
- Discuss the federal and state systems of care that have been developed to address health equity among individuals with developmental disabilities, and the ethical challenges to implementation.

Online registration for the meeting is required at: https://uic.qualtrics.com/SE/?SID=SV_dHa03UVLHACkkt
There is no charge for participating in the meeting. Parking is available ($13 max). Directions will be provided to registered participants. For more information contact Renae Alvarez (ralvar30@uic.edu). The Great Lakes LEND Collaborative includes the MCHB-funded LEND programs in the states of Illinois, Indiana, Ohio (Cincinnati and Columbus), Minnesota and Wisconsin. For more information about these programs, click on the LEND map at www.aucd.org.

Act Early Regional Meeting: Insurance Issues in ASD Screening, Diagnosis, & Treatment

Thursday, October 9th
12:45pm-3pm
University of Illinois at Chicago, College of Nursing
Third Floor Event Center, Chicago, IL

Participants in the afternoon session will be able to:

- Learn about barriers that regional states have faced in providing autism spectrum disorder or developmental screening, diagnostic evaluation, and treatment.
- Identify innovative strategies used by regional states to fund appropriate autism spectrum disorder screening, diagnosis and evidence-based treatment for individuals who are underinsured.
- Strategize ways in which national LEND programs can partner between states to address challenges in providing necessary autism spectrum disorder and developmental screening and evidence-based treatment.
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Morning Session Agenda

- **7:30 - 7:45**  Check-in and refreshments
- **7:45 - 8:00**  Welcome
- **8:00 - 9:00**  Targeted Treatment for the Underlying Disorder in Fragile X Syndrome: Elizabeth Berry-Kravis MD, Rush University
- **9:00 - 9:45**  Interdisciplinary Response Panel: Peter J. Smith, Illinois LEND; Stephan Viehweg, Indiana LEND; Meg Swabeck, Former Illinois LEND Fellow; Beth Dehoff, Former Indiana LEND Fellow; Tara Maga, Former Wisconsin LEND Fellow
- **9:45 - 10:00**  Break
- **10:00 - 10:15**  Personal narrative as parent of child with genetic condition and perinatal hospice: Renee Hepperlin, Former Minnesota LEND Fellow
- **10:15 - 10:40**  Clinical Whole Exome Sequencing: Carrie Atzinger, Cincinnati LEND and co-sponsored by Nisonger Center (Ohio UCEDD/LEND)
- **10:40 - 10:55**  Care Coordination: Empowering Families – A Model for Partnership between Regional Genetics Collaboratives: Title V, LEND and Family Programs: Rylin Rodgers, Indiana LEND
- **10:55 - 11:10**  Genetic Alliance Impact Award to Improve Newborn Screening in Wisconsin Plain Communities: Anne Harris, Waisman Center UCEDD/Wisconsin LEND
- **11:10 - 11:35**  Meet your Neighbor: The Region 4 Midwest Genetics Collaborative: Gina Gembel, Region IV Genetics collaborative
- **11:35 - 11:50**  Discussion
- **11:50 - 12:40**  Lunch (Provided to attendees participating in both morning and afternoon sessions)

Act Early Regional Meeting:

*Insurance Issues in ASD Screening, Diagnosis & Treatment*

Afternoon Session Agenda

- **12:45 - 1:15**  Michigan's Medicaid Applied Behavior Analysis Services and Michigan Resources: Lisa Grost, Michigan Department of Community Health
- **1:15 - 1:25**  Challenges in Medicaid Parity for ASD: Mary Miller, The Autism Program of Illinois
- **1:25 - 1:35**  Financing Autism Treatment in Indiana, a glimpse at the state of the state related to public and private funding options: Rylin Rodgers, Indiana LEND
- **1:35 - 1:50**  Discussion
- **1:50 - 2:00**  Break
- **2:00 - 2:10**  Funding Autism Treatment in Wisconsin: Waiver, Insurance, and Looking Ahead: Joanne Juhnke, Former Wisconsin LEND Fellow
- **2:10 - 2:20**  DHS Autism Policy Benefit Specialist–Updates on new ASD waiver: Kelly Nye-Lengerman, Institute on Community Integration (Minnesota UCEDD/LEND)
- **2:20 - 2:30**  Autism Diagnosis Education Project in Ohio: Paula Rabidoux, Nisonger Center (Ohio UCEDD/LEND)
- **2:30 - 2:40**  Let's Get Energized! Breathing new life into Ohio’s Act Early Activities: Stephanie Weber, Cincinnati LEND
- **2:40 - 3:00**  Discussion and Closing remarks