Leadership Education in Neurodevelopmental and related Disabilities (LEND) Program
Overview of Neurodevelopmental Disabilities and Systems of Care 2017-2018

Course Description
Course Director: Karen Edwards MD MPH

Course Description
The WIHD LEND Training Program consists of three courses: Neurodevelopmental Disabilities and their Systems of Care; Seminar in Evidence-based Methods, and Interdisciplinary Leadership in Action. The Neurodevelopmental Disabilities and Systems of Care course (NDSC) provides a population-based perspective and epidemiology of childhood disabilities and examines key issues in assessment and treatment of children with or at risk for neurodevelopmental disabilities and their families. It also examines the broad context of health care systems and service delivery for children with disabilities from birth through young adulthood with a strong emphasis on family centered practice and family partnership. In addition a module on policy and advocacy provides an understanding of the history of the disability rights movement, landmark federal and state legislation, and court decisions as well as strategies for community advocacy. This two semester course is taught in nine modules: 1) Early Intervention, 2) Autism Spectrum Disorders, 3) Inclusive Education, 4) Genetics and Genomics, 5) Family Partnerships, 6) Policy and Advocacy, 7) Vulnerable Populations, 8) Coordinated Care and 9) Transition.

Course Goals
The learning activities of this course assist trainees to develop a higher level of competency in these MCH Leadership Competency areas: 1) Knowledge Base; 3) Ethics & Professionalism; 5) Communication; 8) Family Centered Care, 11) Working with Communities & Systems; 12) Policy and Advocacy

Course Objectives
Learning Objectives for this course are found in individual module descriptions.

Course sessions are listed here by Module
Early Intervention (EI); Module Coordinator: K. Edwards MD MPH
  • Early Intervention 1: Low Birth Weight
  • Early Intervention 2: Systems of Care and Intervention Settings

Autism Spectrum Disorders (ASD); Module Coordinator: P. Towle, PhD
  • Autism Spectrum Disorder 1: Epidemiology, Diagnosis, and Etiology
  • Autism Spectrum Disorder 2: Treatment Options
  • Autism Spectrum Disorders 3: Guest Speaker

Inclusive Education; Module Coordinator: J. Lequia
  • Inclusive Education #1
  • Inclusive Education #2
  • Inclusive Education #3

Genetics and Genomics; Module Coordinator: J. Villiers, MS, CGC
  • Genetics 1: The Vast World of Genetics
  • Genetics 2: Finding Red Flags in the Family History
  • Genetics 3: Genetic Testing and the Impact of a Diagnosis
  • Genetics 4: Social and Ethical Issues in Genetics and Genetic Testing

Family Partnerships (FP); Module Coordinator: B. Levitz, MSEd
  • Introduction to the Family Partnerships, Policy and Advocacy, and Transition Modules
  • Family-Centered/Family-Directed Practices and Family-Professional Collaboration
• Family Quality of Life and Advocacy Presentations
• Family Support and Family Involvement in Program Planning, Implementation and Evaluation
• Part 1) Family-Focused Disability Organization Interviews: Lessons Learned   Part 2) Focus on Siblings of Individuals with Developmental Disabilities
• Community Advocacy Leadership Interviews Share-back
• Ethics and Family/Professional Partnerships in Healthcare Decision-Making
• Family Mentorship Experience Share-back

Policy and Advocacy (PA); Module Coordinator: B. Levitz, MSEd
• A Framework for Understanding National Disability Policy
• Impact of Community Advocacy on Policy
• LEND Trainee Report-back from AUCD meeting
• Q&A with the New York State Dept of Health: State Level Policy Concerning Children

Vulnerable Populations (VP); Module Coordinator: D. Weisberg, CSW
• The Developmental Risks Resulting from Exposure to Abuse and Neglect
• Child Abuse/Child Welfare: A Public Health Perspective;
• Child Abuse and Neglect: A Multidisciplinary Model for Assessment
• Systems of Care Approaches in Child Welfare

Coordinated Care (CC); Module Coordinator: K Edwards, MD, MPH
• Children with Special Health Care Needs (CSHCN) and the Public Health Perspective
• Life Course Theory and Social Determinants of Health: Life Course Game
• Introduction to disabilities
• Overview and Evaluation of Children with Motor Impairments
• Identification, Evaluation and Habilitation of Pediatric Hearing Loss
• Bilingualism
• Challenging Behaviors

Transition (TM); Module Coordinator: B. Levitz, MSEd
• Self-Determination and Self-Advocacy
• Person-Centered Planning for Transition from School to Post-Secondary Education, Integrated Employment and Community Living
• Health Transition and the Medical Home
• Aging and Disability

Course Assignments and point values:
1. Attend in-class sessions (5 points)
2. Participation and Completion of pre-assignments for each session (10 points)
3. Family Focused Disability Organization Interviews (15 points)
4. Family Mentorship Experience (20 points)
5. Mid-year Reflective Writing Exercise (15 points)
6. End of Year Reflective Writing Exercise (20 points)
7. Community Advocacy Leadership Interviews (15 points)