



Leadership Education in Neurodevelopmental and related Disabilities (LEND) Program

How Life Course Theory (LCT) and Social Determinants of Health (SDOH) have been incorporated into LEND Family Partnerships Training:

1. Family Mentorship Home-Visiting Experience
2. Family-Focused Disability Organization Interview
3. LEND Family Partnerships Curriculum Module

The LEND Program at WIHD has incorporated LCT/SDOH elements into its Family Mentorship home and community visiting experience and the family-focused disability organization interview as well as the Family Partnerships Curriculum Module. The goal is to help trainees develop a deeper understanding of the family as the environment in which children grow and develop, and to provide trainees an opportunity to listen to and reflect upon what families share about support systems and how cultural and social issues impact on the acceptance and inclusion of children, youth and adults with disabilities in family and community life.

Incorporating LCT-SHOH into the LEND Family Mentorship Experience:

This has been accomplished in the Family Mentorship experience through the simple strategy of adding life course issues into an existing pre-visit listening guide. Each trainee is instructed to review this guide prior to visiting with his or her mentor family as preparation for the kinds of topics they should listen for or to encourage the family to address while sharing their personal stories and life experiences. Trainee do not work directly from this form during the home visit but rather use the form only as a guide since the Family Mentorship experience is not intended to be a question and answer interview. This pre-visit listening guide now addresses LCT by including an additional question: *In what ways, if any, have cultural and social issues impacted on the acceptance and inclusion of their child/children with disabilities within their family and community?* Another question in the pre-visit listening guide has been enhanced by expanding this question to address life course: *What are the professional disciplines and/or interdisciplinary teams with which the family has interacted at various stages throughout their child's lifespan?*

These guiding questions are also used as a framework for a Family Mentorship experience group discussion based on trainees completing a Post-visit Impressions and Reflections form. One of the key questions added to address LCT/SOHOH is: *How did this experience influence your views on disability, family and culture?* Additionally, another question has been enhanced to

incorporate LCT-SDOH: How will this experience change your approach to working with families of children, adolescents or young adults with disabilities *throughout the lifespan*?

Incorporating LCT-SHOH into the LEND Family-Focused Disability Organization Interview:

Families often express that the most helpful information and support they receive has been from other families, particularly those associated with parent support and advocacy groups, parent-staffed centers, and family support providers. LEND Trainees at the Westchester Institute for Human Development also complete a leadership assignment to conduct a guided interview with a family-focused disability organization of their choice with faculty approval. Trainees complete a post-interview notes form and then share this information through a brief presentation and discussion including highlighting the organization's website group. For this project assignment, two interview questions were added to address LCT-SDOH:

- In what ways, if any, do cultural considerations and socio-economic factors impact on how the disability organization assists and supports families of individuals with disabilities and special health care needs?
- Does the organization assist families of individuals with disabilities throughout the lifespan or does it specialize in a particular phase in life?

Incorporating LCT-SHOH into the LEND Family Partnerships Curriculum Module:

A session on *Family Quality of Life, Family Advocacy and Life Course Theory* has been added to the LEND Family Partnerships Curriculum Module at WIHD that introduces these topics through a family faculty PowerPoint presentation, based on the FQOL construct developed by the Beach Center on Disabilities at the University of Kansas; followed by LEND family discipline trainees sharing their personal stories and experiences through presentations on Family Quality of Life and Advocacy. Additionally, as part of the curriculum session on *Partnerships in Family Advocacy, Family Support, and Family Involvement in Program Planning, Implementation and Evaluation*, a panel of UCEDD/LEND parent staff share their first-hand experiences during a facilitated discussion that now also includes a focus on LCT-SHOH. Family staff members respond to the following new or expanded questions:

- How have the outcomes of your early advocacy efforts impacted on your child's life now, from a life span perspective?
- Have social, cultural, disability, health or other family issues impacted on how your child has been included in family and community life?
- What informal/natural supports have been most helpful to your family at different points throughout your child's life?
- What specific kinds of family support services, community resources and formal systems have been most helpful to your family at different points throughout your child's life?