



**A.J. Pappanikou Center for Excellence  
in Developmental Disabilities  
Education, Research and Service**



**Leadership Education in Neurodevelopmental and Related Disabilities  
Program**

# Family Faculty Guide

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# Background

- In 2005 the Maternal and Child Health Bureau adopted the following as the definition of family centered care:
  - *Family-Centered care assures the health and well-being of child and their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions and expertise that everyone brings to this relation. Family-Centered Care is the standard of practice which results in the high quality services.*
- This definition led the MCHB to mandate all LEND programs to include family involvement in the training of emerging professionals

# Background

- Research
  - Websites:
    - 50 UCEDD websites
      - Mountain Plans Regional Resource Center: *An Educator and Parent Primer on Special Education, Acronyms, Abbreviations, and Definitions*
      - Florida Center for Inclusive Communities: *Glossary of Frequently Used Acronyms*
    - 39 LEND websites
      - UCONN LEND: Long-term Trainee/Fellow Handbook
    - AUCD
      - LEND program brochure
      - History of LEND
      - Family Discipline Competencies
      - Resource for the glossary of acronyms and definition of commonly used terms
    - Family Voices
      - Family centered care resource
    - Disability is Natural
      - Person first language resource

# Background

- Research continued
  - Family training session
    - Gained insight:
      - Into family leadership
      - That every person has different experiences as a family member of an individual with a disability especially across generations
    - Families as Advisors presentation-Molly Cole
  - Personal Interviews
    - Questions:
      - What does the word leader mean to you?
      - What has been your experience as a member of the Family Faculty?
      - Any tips for potential new family faculty members?

# Purpose

- To provide family faculty members with information about the LEND program, their role as family faculty, and resources to further their understanding of the variety of competencies addressed in the LEND curriculum

# Methods

- Participants: three members of the family faculty
  - Utilized for interviews for personal story section of the guide and feedback once guide is finalized
- Expected results/implications: members of the family faculty feel prepared in their role
  - This includes but is not limited to
    - Being a resource for emerging professionals
    - Aiding the presenter in illustrating an objective
    - Recounting personal experiences
- Further research: assess the validity of the guide utilizing members of the faculty who were involved before and after the guide was developed

# Guide Format

- Introduction
  - Importance of family faculty based on the principles of family centered practice
  - Purpose for guide
- Overview of the LEND program
  - History
  - About the fellows
- Role of Family Faculty
  - Qualifications
  - About the program at UCONN
  - What the members of the faculty will gain
- Interviews with Family Faculty
  - What is a leader?
  - What has been your experience as a member of the Family Faculty?
  - Advise for new members?
- Resources
  - Glossary of Acronyms
  - Definition of Common Terms
  - Person First Language
  - Helpful Websites
- References

# References

- Definition of Family Centered Care. MCHB DSCHN. 2005