Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Program

The Division of Developmental and Behavioral Pediatrics
Cincinnati Children's Hospital Medical Center
The University of Cincinnati University Center for Excellence in Developmental Disabilities

Family Mentoring Project
Coordinator: Sheryl Feuer, LEND Family Faculty

The Vision of the Maternal and Child Health Bureau (MCHB) is for a future America in which “all children, youth and families will live and thrive in healthy communities served by a quality workforce that helps assure their health and wellbeing.” Therefore, quality services for mothers, children and adolescents require professionals who are:

- Attuned to the special needs of children, adolescents and children with special health care needs
- Trained to provide or assure the provision of interdisciplinary, family-centered, and culturally competent services
- Focused on improving the health of the entire population

The purpose of the Family Mentoring Project (FMP) is for LEND trainees to gain a better understanding of the issues involved in raising a child with a disability and the value of forming collaborative partnerships with the families they serve.

Each trainee (either individually or in pairs) is assigned a volunteer mentoring family, with whom they will arrange three (3) visits over the course of the 9-month LEND program (one visit per quarter). The first visit will take place in the family’s home. The second and third visits will be held at community-based venues agreed upon by both parties. In conjunction, classroom activities will provide trainees with opportunities to reflect on their own life course perspectives and to broaden their insight into the families’ strengths and the challenges and rewards they face.

Following the completion of the visits, the trainees will each write a personal essay assimilating their experiences and describing the project’s impact on them as healthcare professionals.
Family Mentoring Project

FAMILY MENTORING PROJECT GOALS AND OBJECTIVES

Through participation in the Family Mentoring Project, LEND trainees will:

MCH Leadership Competency #1: Knowledge Base/Context
- Recognize the impact a child with a developmental disability or other special healthcare needs may have on the family, health professional and society
- Assessment through completion of three (3) family visits, participation in classroom discussions, written responses to assigned readings, and personal reflection essay

MCH Leadership Competency #4: Critical Thinking
- Increase awareness of personal attitudes/biases, and philosophical, emotional or ethical beliefs that can impact a professional’s relationship and collaboration with families of children with developmental disabilities or other special healthcare needs
- Assessment through completion of Personal Perspective classroom activity; personal reflection essay

MCH Leadership Competencies #7: Cultural Competency and #8: Family-Centered Care
- Recognize and implement concepts of family-centered practices, linguistic access and cultural competence when working in partnership with families of children with developmental disabilities or other special healthcare needs
- Assessment through participation in classroom activities; completion of the family mentoring experience

MCH Leadership Competency #11: Working with Communities and Systems
- Experience community participation by children with developmental disabilities or other special healthcare needs and their families to become aware of the availability and appropriateness of services, supports and resources
- Assessment through completion of family visits in the community, participation in classroom discussions (Family-Centered Care, Personal Perspective-Taking), written responses to assigned readings, and personal reflection essay
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## Family Mentoring Project

**TRAINEE TIMELINE**

*Deadline requires you to make a submission to Blackboard.*

<table>
<thead>
<tr>
<th>Date/Deadline</th>
<th>Activity</th>
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<tbody>
<tr>
<td>Aug. 30</td>
<td>Family Mentoring Coordinator presents project overview as part of LEND Orientation</td>
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<tr>
<td>By midnight, Sept. 4</td>
<td>Complete FMP Trainee Pre-Match Survey on Constant Contact</td>
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| *By midnight, Sept. 25* | Pre-class assignment for Session 1: Read article and submit answers to discussion questions to Blackboard  
  • *Article: Perspective Taking: Misstepping into Others’ Shoes.* |
| Oct. 2         | FMP Session 1: FMP in Detail and Personal Perspective  
  • Review of project expectations and guidelines  
  • Mentoring families assigned  
  • Personal perspective exercise |
| *By midnight, Oct. 9* | Contact mentoring family - schedule 1st visit *(in the home)* and submit the planned date to Blackboard |
| By Nov. 20     | 1st visit with mentoring family (in the home)  
  • Document all interactions (phone, email, in-person) with the family on the Family Mentoring Log Form (in Blackboard under Course Folder) |
| *By midnight, Nov. 22* | Submit initial FMP log form to Blackboard |
| *By midnight, Nov. 29* | Contact mentoring family - schedule 2nd visit (community location) and submit date to Blackboard |
| By Jan. 24     | 2nd visit with mentoring family (community location) |
| *By midnight, Jan. 26* | Submit updated FMP log form to Blackboard |
| *By midnight, Jan. 31* | Contact mentoring family -- Schedule 3rd visit (in community) and submit date to Blackboard |
| By Mar. 7      | 3rd visit with mentoring family (community location) |
| *By midnight, Mar. 14* | Submit updated FMP log form to Blackboard  
  • Submit pre-class assignment (TBA) for Session 2 to Blackboard |
| Mar. 26        | FMP Session 2: Assimilating the Experience  
  • Review of FMP goals/group discussion/activity  
  • Guests: 2012-2013 FMP family mentors  
  • Group sharing of trainees’ FMP experiences  
  • Review of personal essay requirements |
| *By midnight Apr. 9* | Submit personal essay to Blackboard |
| *TBA*          | FMP Trainee Evaluation Form completed and submitted to Constant Contact at the same time as other end-of-year LEND evaluations |
**Family Mentoring Project**

**TRAINEE GUIDELINES**

**Family Visit Requirements**
The FMP requires (3) three meetings (*no less than one hour each*) with a volunteer family of a child with a disability. The first visit should be in the family’s home. The others should be held in two different community locations. (Examples: I.E.P. or teacher meeting, a classroom observation, therapy session, sporting event, playing at the park, shopping, birthday party, family gathering)

**Before Contacting the Family:**
- Identify days and times you will be available for visits.

**Scheduling Family Visits:**
- DO NOT procrastinate! You and your mentoring family are both busy, so schedule your visits early. This will help you meet the deadline requirements, by allowing you time to reschedule a visit, should something unforeseen require you or your mentoring family to cancel it. If you have trouble keeping in touch with the family or scheduling visits, contact the FMP Coordinator immediately.
- Document all contact with family using the FMP Log Form (see below).

**After Scheduling a Visit:**
- Notify the FMP Coordinator by e-mail ([sheryl.feuer@cchmc.org](mailto:sheryl.feuer@cchmc.org)) with the time and location of each visit at least 5 days in advance.
- Confirm the visit with the host family a few days in advance. Remember to be flexible. Busy schedules and the demands of everyday family life may impact the family’s availability.

**Preparing for Visits:**
- Attend FMP Session 1 for the project overview.
- Review the following documents to help you focus on the project objectives:
  - Family Discussion Guide (below)
  - Your completed Personal Perspective Worksheet from the first FMP Core session
  - Rubric for the essay you will write at the end of the project. It will provide you guidance. (Located under the course folder in Blackboard)

**The Visits:**
- The initial visit will take place in the family’s home. The second and third visits should be held in a community.
- Prepare to be a student and avoid offering professional advice or suggestions. The purpose of the visits is to *observe* the family’s experiences, not just the child’s disability, and relate them to your life course perspective and professional practice. Acknowledge siblings and other members of the family. They often have a unique story to tell.
- Remain respectful and non-judgmental. Go with an open mind.
- At the end of the 1st and 2nd visits, see if you and your mentoring family can determine a date and location (as early as possible) for the next one.
- If you are scheduled for a visit with your mentoring family and develop an illness, even if it’s minor and not interfering with your activities, contact your family in advance to see if they would like to reschedule.
FMP Log Form:
- Use the FMP Log Form (located under course folder in Blackboard) to document all contacts (phone, e-mail, face-to-face) with your mentoring family. You will find the form under “FMP Overview and Related Materials” in the FMP folder in Blackboard. Please save it to your computer as a Word document. This will allow you to update and post it to Blackboard as required (see Trainee Timeline).

Privacy and Safety Considerations:
- HIPAA regulations protecting personal and health information apply to this visit. Any information learned from the family is confidential. When participating in class discussions or writing about the experience, all personal identifiers must be omitted. Discussion of the visits should not be shared with anyone outside of LEND.
- Guidelines for professional relationships apply. The family has been informed that an adult must remain with the child at all observations. Trainees should not transport families or provide baby-sitting or other services for the family. Money and gifts should not be exchanged.
- Personal safety is a priority.
  - Call ahead to confirm the visit with the family.
  - If possible, carry a cell phone on visits, preprogrammed with important numbers (i.e. 911, FMP Coordinator and Training Director — listed below).
  - Always carry ID.
  - Become familiar with the geographic area of meeting locations for the family visits.
  - Park in well-lit areas and as close to the meeting location as possible.

After Visits:
- Record visit experiences on the FMP Log Form and submit it to Blackboard by the due date. These will serve as a reference for your final essay at the conclusion of the project. Only the FMP Coordinator will have access to these completed forms.
- After the 1st and 2nd visits, immediately contact the family to thank them for their time and, if you have not already done so, schedule your next visit.
- After the final visit, please send a card or note of appreciation to your mentoring family.

For any concerns, contact:
- Sheryl Feuer, FMP Coordinator: 513-803-3364 (work), 513-522-7155 (home), or 513-504-3919 (cell) or
- Roz Parrish, LEND Associate Director: 513-636-4619 (work), 513-477-5943 (cell)
Family Mentoring Project

FAMILY VISIT DISCUSSION GUIDE

The questions below should serve as a guide (not a script) to topics and issues that you might discuss with your mentoring family to help you address the FMP goals and objectives.

1. How does the family define their child’s disability (e.g., challenges, strengths)?
2. Who lives with the family?
3. What are their living arrangements (e.g., private home, apartment, government housing)?
4. What, if any, insurance does the family have (e.g., private, Medicaid, both)?
5. Who in the family makes the major decisions?
6. In what ways do the parents advocate for their child?
7. What does the family consider their greatest strength?
8. In what ways do they feel raising a child with special needs has had an impact on their family?
9. How has the family partnered with professionals in advocating to meet the needs of their child/children with special needs?
10. In what ways, if any, have cultural experiences had an impact on the acceptance and inclusion of their child with special needs within the family and community?
11. With what professional disciplines and/or interdisciplinary teams have the child and family interacted?
12. What does the family consider their top priority in raising their child with special needs?
13. Does the child participate in activities with other children with and without disabilities in the community?
14. What, if any, challenges have they faced dealing with their child’s school(s)?
15. What interventions/accommodations does the school provide for their child? Does the family feel these are adequate and/or appropriate?
GUIDE TO FAMILY STRESSORS

Social stressors and life circumstances:

- Household Members
- Income/employment
- Violence in the neighborhood/family
- Access to healthy foods/food insecurity
- Housing/homelessness
- Literacy
- English proficiency
- Child care
- Family support system
- Communication barriers (internet/phone)
- Transportation
- Disability

How these stressors might impact the clinician or the clinical encounter:

- Late or missing appointments
- Medication/treatment follow thought
- Children distracted or whiny because they are hungry or in unfamiliar settings
- Weight challenges (no exercise, lack healthy food)
- Fearful of divulging information
- Scheduling issues (due to employment/transportation)

What can the professional do about stressors and life circumstances?

- Offer help/resources
- Follow up supports
- Prioritize recommendations; provide information in a “usable” fashion
- Empathy
- Empowerment