

Cincinnati Children's Hospital Medical Center
Division of Developmental and Behavioral Pediatrics
Leadership Education in Neurodevelopmental Disabilities

**Family Mentoring Experience
Trainee Orientation Manual
2005-2006**

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Objectives:

- To experience first hand what it is like to raise a child with a developmental disability/special health care needs in order to recognize and develop sensitive and realistic treatment plans and interventions in the trainees' future practices as professionals
- To learn to identify and appreciate family strengths that will encourage the trainees in their future practices to develop treatment plans and interventions that capitalize on those strengths
- To recognize the similarities between families with and without developmental disabilities/special health care needs in order to promote community inclusion
- To recognize how programs and policies effect families of children with developmental disabilities/special health care needs in order to develop leadership skills necessary to promote positive systems change
- To recognize effective parental advocacy skills and how they impact a family's ability to effect systems change for their child with a developmental disability/special health care needs

Leadership Competencies Addressed

Environmental Factors

Micro (Family) Environment:

- Identify stages of adaptation and parental reactions to being the parent of a child with a neurodevelopmental or related disability.
- Identify practices and approaches that support the empowerment of families.
- Identify issues related to the assessment, intervention, and access to services of African-American and/or Appalachian children.
- Identify the values, beliefs and customs that may impact child development, child-rearing patterns, and interactions with health professionals of African-American, Appalachian, Hispanic American, Asian American, Native American and /or Amish families.
- Discuss the guidance/interventions needed in childhood to assist families in preparing for transition to adulthood (i.e. beginning work ethic, sexuality, etc.).
- Obtain a clear understanding of caregiver concerns, using communication skills that promote free and open dialogue with families.
- Develop knowledge of the neurodevelopmental disability of his/her mentoring family's child.
- Knowledge of normal growth and development as it pertains to the disability of his/her mentoring family's child.
- Identify how family and professional partnerships enhance systems of care

Meso (Community) Environment:

- Identify the roles of primary, secondary and tertiary systems of care.
- Identify the importance of the medical home and issues related to linking primary, secondary and tertiary level services.
- Identify the health, education, mental health, social service and family support private/public systems of services.
- Discuss issues related to the access and integration of children with/or at risk for neurodevelopmental disabilities and their families into the private/public systems.
- Identify the rationale, benefits and limitations of systems, models, and approaches to prevention, early intervention, assessment, service coordination, treatment/intervention, and home-based care.
- Establish effective working relationships with the family and interdisciplinary colleagues.
- Acknowledge alternative viewpoints through engagement in positive discussion.
- Identify advocacy skills that facilitate cooperative involvement of family and child in community systems.

Macro (Society/National) Environment:

- Discuss how professionals and parents can influence the legislative process and public policy related to the field.
- Identify the social, behavioral, political and economic factors that place children at risk.
- Identify current models of health care and discuss their impact on the field.
- Identify legal, moral and ethical issues related to the field (i.e. access to care, prenatal diagnosis, genetic counseling, treatment/non-treatment, “labeling”, culturally appropriate assessment, etc.).
- Identify community resources.
- Identify the elements necessary for effective collaborative relationships with representatives of a variety of health, education and human service agencies.
- Identify components of service coordination in cooperation with the family and representative of other agencies.

In addition to the Micro, Meso and Macro environmental competencies, the trainee will develop competencies in the following areas as they pertain to his/her Family Mentoring Experience:

- Reflect on and examine his/her own cultural background, biases and prejudices related to race, culture and life-styles that may influence his/her behaviors.
- Evaluate his/her performance in the FME.
- Demonstrate cultural competence in interactions with others.
- Establish rapport with children, families and professionals.

Requirements

1. **Total Hours for the Family Mentoring Experience:** The FME comprises 40 hours of your LEND training. Breakdown by activities is as follows:

- 20 hours: family visits
- 5 hours: orientation and safety training
- 6 hours: three quarterly meetings
- 4 hours: phone calls/e-mails to family (based on one 30-min. call a month)
- 5 hours: journal, evaluation, letter of appreciation, other miscellaneous

2. **FME Orientation:** We will meet September 27 from 1 to 3 p.m. to review this manual and answer any questions you may have about the mentoring program. Attendance is required. If you truly cannot attend, you will need to meet with the Parent Coordinator, Sheryl Feuer, soon after to cover the information you missed.

3. **Safety Training:** CCHMC's Protective Services will discuss safety issues in relation to the Family Mentoring Experience on October 11 from 1 to 3 p.m. Attendance is required. See "Safety Issues" below.

4. **Family Visits:** It is *your* responsibility to contact the family to schedule visits. Your family will be expecting your first call during the first two weeks of your LEND training. Be prepared to schedule your first visit at that time. You'll want to space out the visits over the course of the academic year, so you don't run out of time toward the end of the year and so you'll have something to offer in the way of experiences and reflects at the quarterly group discussions.

Plan to call your mentoring family a day or two before each visit to confirm that the visit is still on. This is not only a courtesy, but may be essential if the family has a lot going on, and they probably will. Also, be sure to call your family immediately if you find that you cannot keep a scheduled visit or make a scheduled phone call. Be sure to reschedule.

You are required to let your faculty advisor and the Parent Coordinator know the time and location of each family visit several days in advance.

Transportation to and from family visits as well as mileage costs are your responsibility. If you have a problem with either (e.g. no car), let the Training Director and Parent Coordinator know so we can consider options.

Your first visit will be just to get to know the family members and learn their family history. You may want to spend time talking with the caregiver(s) alone, without the child(ren) present. This will allow you and the caregiver(s) to speak more openly.

The remaining visits can be held wherever you and the family determine. The following are a few examples:

- Attending an I.E.P. meeting
- Taking a trip to the grocery store
- Accompanying the family to the doctor or therapist
- Participating with the family at a recreational outing
- Eating dinner at their home or a restaurant
- Visiting with other family members, extended family or friends who play a big role in the family's life
- Observing the child in the classroom

As you develop a relationship with your mentoring family, seek to acquire an in-depth understanding of the disability/disabilities with which the family lives, and to gain a real understanding of each member of the family. If the child with special needs lives with both parents, you may notice that the father handles things differently than the mom. Work to understand the perspective of each family member. Depending on the child's age, s/he may wish to share his/her unique perspective. Let the child tell his/her story if s/he chooses. Be mindful to pay special attention to siblings if there are any. Brothers and sisters need to feel included in the FME. Sibs also have their own unique perspectives on living in a family with a disability. Let the children know that you're coming to see them too, not just their caregiver(s). Don't be afraid to play with the kids! They will love it, and you'll learn from it.

Always be careful about what you are saying and who may be listening. Even very young children absorb the feel, if not the actual meaning, of things that are said about them. Do not talk in front of the child(ren) about issues such as the special child's diagnosis, challenges, behavior problems, adoption, previous history of abuse, serious medical conditions, etc, unless the caregiver(s) give(s) the okay. In general, it's a good rule of thumb not to speak about a child in front of that child. Obviously, this rule doesn't apply if the child is an infant or if the child is older and understands his/her disability and feels comfortable talking with you about it.

Once you are comfortable with your mentoring family, make a point of telling them how valuable it is for you to see the entirety of their lives. Families naturally want to show their best side to the outside world, including you, and they often need to be gently but directly told that it's OK to show their weaker, needy, down side, too—and that if they want to share it, you will listen and learn from that, too, without judging them in any way.

Ask your mentoring family how professionals have been helpful to and supportive of them, and also about those times when professionals have not been helpful and supportive. Think about how their answers can help you be more responsive and helpful to future families in your own professional practice.

Always keep in mind that it is an honor and a privilege for you to be welcomed into this family's life. Learn all that they are willing to teach you, and always show respect and appreciation for their willingness to allow you into the very personal and private world of

their family life. Keep your promises and be dependable. If you disagree with something or feel you know better, be sure to listen and think before you speak.

5. Monthly Phone Call/e-Mail: Be sure to contact your mentoring family monthly to keep up with them between visits. Record your calls or e-mails in your journal. It may be helpful to set a mutually agreeable time for you to call (ex. second Tuesday evening of every month). Write it in your calendar! You usually will be talking to a parent, but you may talk with the children or perhaps an extended family member who spends a lot of time in the home.

Be sure to call at a time when you really have the time to listen and be attentive. Ask them at the start of the conversation whether this is a good time for them to chat. If not, ask them when would be a good time. If you have a hard time reaching the family, keep trying.

Some families may prefer that you keep in touch by e-mail. Some families may be willing to send you a monthly schedule of their upcoming activities so you can identify possible opportunities for a visit. Be sure to reply to every e-mail you receive from your mentoring family, even if it's just to let them know you received it.

Whether you are phoning or e-mailing your family, it's always your responsibility to stay in contact with the family.

6. Journal: All family visits, phone calls and e-mails should be recorded in your journal. The purpose of the journal is to allow you to reflect in writing on your experiences in the FME. Your journal must be submitted to the Training Director, your faculty advisor, and the Parent Coordinator for review one week prior to the quarterly FME group discussions. You may either e-mail your entries to these faculty members or submit them on paper.

Be sure to maintain confidentiality in your writing by avoiding any identifying information about your mentoring family. There is no set format for these entries. Your first entry should include a brief, informal family history, diagnosis and treatments along with your reflections. Record your observations and experiences with your family, your feelings and thoughts, what you feel you have learned from the experiences, and how you think the experiences might affect the way you work with the children with special needs and their families in your professional practice. Keep in mind the objectives and competencies for the FME (pages 1-2). Some questions you might ask yourself are:

How does this child's disability impacts the family emotionally, economically, etc.?

How, specifically, is this family like and unlike other families who do not have a child with a disability?

How do the family members cope on a daily basis?

What are the family's strengths?

Pay attention to experiences with your mentoring family that surprise you or challenge your values or your way of thinking.

Journal entries will not be shared with the family.

7. Quarterly Group Discussions: You will meet three times with your fellow trainees over the course of your FME. This will give you the opportunity to share your experiences with the others and to learn from their experiences in turn. This exposes you to a variety of experiences, allowing you to appreciate the diversity in families of children with special needs. Confidentiality will be observed.

8. Written Evaluation of the FME: At the end of the year, you will turn in an anonymous evaluation of the FME. This will provide us with feedback that will help us improve the program.

9. Letter of Appreciation to Family: As a common courtesy, you will formally thank your mentoring family in writing to express your appreciation for sharing their time and expertise with you. You should take this opportunity to highlight some of the competencies you feel they helped you meet.

Roles of Family and Trainee

In the Family Mentoring Experience, the family is the mentor, you are the student. You are there to listen, observe, and ask questions. Feel free to serve the family's needs as a sounding board, a resource, or an extra pair of hands, but remember that you are not to offer advice and suggestions.

The Parent Coordinator has made home visits to each family. They have received a manual similar to this one, but shorter and geared toward the role of mentor. These are families who have demonstrated an eagerness to share their lives and experiences with LEND trainees with the hope that their mentoring will have a positive impact on health care systems.

There may be times when the line is unclear between your role as learner and your experience as a professional. Your family may seem to need resources or advocacy that is beyond the scope of your role in the FME. If this is the case, please contact the Training Director or Parent Coordinator so we can determine the best way to handle it.

We try to select as diverse a group of families as possible. We seek diversity in age, disability, race, culture, family structure and home settings. As a result, you may be confronted with values and/or child-rearing practices that differ from your own. Although this may make you uncomfortable, *you must remain respectful and non-judgmental in your relationship with your mentoring family.* Keep in mind that you represent the Division of Developmental and Behavioral Pediatrics' LEND program.

The following activities are prohibited during the academic year of your FME:

- baby-sitting or providing any other services for your mentoring family
- transporting any mentoring family members in your car
- the exchange of money or gifts between you and your mentoring family
- the consumption of alcoholic beverages or recreational drugs while visiting your mentoring family

Confidentiality in the Family Mentoring Experience

Do not discuss your family mentoring experiences with your friends, family members, or anyone else not associated with the LEND program. You are, however, required by law to report any abuse or neglect. If you feel you have witnessed abuse and/or neglect within the context of your FME, notify your faculty advisor and the Training Director immediately.

When you write in your journal or share with the LEND group, do not use the last name(s) of the family members. Keep your journal private. Outside of the group discussions, do not share your journal with anyone other than your LEND faculty advisor, the Training Director, and the Parent Coordinator.

Checklist for Your First Visit or Call

- Have your day planner or calendar with you.
- Find out who your primary contact will be.
- Review with the family your understanding of your respective roles in the FME, your commitment to calls and visits, your practice of confidentiality, etc.
- Exchange phone numbers and alternative methods of contact (cell phone numbers, e-mail addresses, pager, work numbers). Determine the best ways to reach each other.
- Share good and bad times to call. (For example, the child's bed time may not be the best time to call your family.)
- Ask your family if it would be helpful to them to set a certain day of the month and time of day for your monthly calls. Be sure to record it in your planner.
- Ask your family to share any house rules or cultural issues of which you need to be aware.

- Ask your family about any parking or safety issues you should know about.
- Set the date, time, and place for your next call or visit.

NOTE: You and your family may want to line up some or all of the other visits in general terms – for example, attend the child’s birthday party, attend an IEP meeting, go to the playground in the spring, etc. You may not be able to set exact dates and times during this first visit, but you’ll have a general idea of what experiences the family thinks you should observe.

Coordinating Schedules with Your Mentoring Family

Coordinating your schedule with that of your mentoring family is likely to be your biggest problem with the FME. Remember, it is always your responsibility to keep in touch with them. If you find you’re playing phone tag or your family hasn’t returned your call within a day or two, keep trying. If, however, you have been persistent in trying to contact them, but have not been able to reach them over the course of a few weeks, let the Parent Coordinator know. It’s possible that something unforeseen has come up for the family and they are not able to continue with the program. If this happens it’s important for the Parent Coordinator is notified quickly so an alternative mentoring family can be arranged.

Be sure to log every call and visit in your journal. This will help you keep track of your FME hours and keep you from falling behind. It will also help you follow through on your commitments and deadlines. Remember that LEND is a leadership training program, and leaders meet their commitments and deadlines.

The Importance of E-Mail

Communication between LEND trainees and faculty regarding the Family Mentoring Experience is heavily dependent on e-mail. Be sure to check your e-mail daily. Be considerate and respond to e-mails in a timely way. If you experience computer problems and are unable to check your e-mail, let the Parent Coordinator know as soon as possible.

Safety Issues

Although the Parent Coordinator has screened families for this program, the issue of your personal safety remains a priority. Unforeseen situations can always arise, even in the best neighborhoods. *If at any time you feel uncomfortable or at risk during a family visit, leave immediately and call 911.* We can always match you with another mentoring family. You will not be penalized. You are required to carry a cell phone at all times when on family visits. Be sure to give the times and locations of each family visit to the Parent Coordinator several days in advance. Familiarize yourself with the “Safety Tips

for LEND Trainees on Family Visits.” If a situation arises that you’re unsure about while on a family visit, you may call the Parent Coordinator, Sheryl Feuer, at 636-4626 (work), 522-7155 (home), or 513-508-9586 (cell phone), or the Training Director, Roz Parrish at 513-477-5943.

Problematic Situations

Once you get started with your FME, you may run into a problematic situation. Below are some hints that may help you avoid these possible pitfalls.

Evaluate your FME match early in the relationship. If you find early on that you’re not relating well with this family, and you’re sure it’s not going to work out, let the Parent Coordinator know right away so you can be assigned another mentoring family.

Be a consistent, reliable communicator. If you are truly unable to reach your mentoring family by phone or e-mail, or if scheduling conflicts are making it difficult to meet your FME requirements, inform the Parent Coordinator, who will track down the family for you and help you reconnect.

Maintain your role as the student. If you find you’re having trouble remaining objective with your family, or if you have concerns regarding the family that you feel go beyond cultural differences or values, tell your faculty advisor, the Training Director and the Parent Coordinator.

Keep your FME commitments. Open, honest and timely communication among trainees, faculty and the families is essential. Let the Parent Coordinator know if you are running into problems with your mentoring experience. Missing visits or calls, work turned in late, and unexcused absences are unfair to your mentoring family and a waste of their time. You are expected to keep your commitments.

On-going Support

It is important for you and the Parent Coordinator, Sheryl Feuer, to stay in close contact during your FME in order for the experience to go smoothly for you and your mentoring family. Please call Sheryl with any concerns or suggestions during your FME. She can be reached at work at 636-4626 or by GroupWise e-mail. Feel free to call her at home at 522-7155 or by cell phone at 513-508-9586.

Remember, this is a unique experience. Enjoy it and learn all you can from your mentoring family!