



Division of Developmental and Behavioral Pediatrics
Leadership Education in Neurodevelopmental Disabilities

Family Orientation Manual Family Mentoring Experience

Overview of the Family Mentoring Experience

The Family Mentoring Experience (FME) is a required part of the Division of Developmental and Behavioral Pediatrics' Leadership Education in Neurodevelopmental Disabilities (LEND) program, which is funded through the federal government's Maternal and Child Health Bureau. The purpose of the LEND program is to train professionals to be leaders in their fields by stressing interdisciplinary, family-centered care.

The Family Mentoring Experience is a program in which families like yours help train professionals who work with children with disabilities and their families. LEND trainees represent various disciplines, such as pediatrics, occupational therapy, physical therapy, social work, nutrition, audiology, speech pathology, nursing and psychology.

Each family has a trainee assigned to them. Your job will be to show the trainee what it is like, in your own personal experience, to have a child with a disability. We hope you will share your feelings and experiences, including the good times and the bad times, so that your trainee can see "the whole picture" of what it is like to be a family of a child with special needs.

Objectives for Trainees

Professionals who serve families of children with disabilities usually do not have the opportunity to see their clients in "real life" settings, such as the home, the playground, grocery store, restaurant, etc. The Family Mentoring Experience is your chance to show one professional (your trainee) the "bigger picture" of your family's life, in order to help the trainee with the following 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 trainee's future practice as a professional
- To learn to identify and appreciate family strengths that will encourage the trainee in his/her future practice 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

Time Commitment

1. One home visit by Parent Coordinator during the summer prior to the start of the program. (This visit will be to go over the program and answer any questions you may have.)
2. Review and sign Authorization for Use and/or Disclosure of Protected Health Information form prior to trainee's first visit. (This form gives the trainee your permission to share your child's private health information in the confidential manner clarified in this manual. We will have you sign the form in the fall after we match you with a trainee.)
3. Trainee visits totaling twenty hours over the course of the academic year (October to June)
4. One phone call or e-mail exchange monthly with your trainee. (It is your trainee's responsibility to call you.)
5. Occasional phone calls from the Parent Coordinator throughout the academic year to hear how the experience is going for your family.
6. Completion of evaluation form at end of year.

Details of the Family Mentoring Experience Commitment

1. **Trainee visits:** Your trainee will contact you early in October to schedule his/her first visit with your family. The visits can be at your home or another activity that

you feel would help your trainee see what your family's life is like. You or another adult must be with your child and the trainee at all times during these visits. Trainees are not permitted to provide childcare or babysitting for their mentoring family during the Family Mentoring Experience year.

2. **Monthly phone calls or e-mails:** Your trainee needs to stay in touch with your family in-between visits to keep up with what has been happening in your family since the last visit. Your trainee will ask you about the best ways and times to contact you. It is the trainee's responsibility to contact you. However, if he/she e-mails you or leaves a phone message for you, we ask that you please reply to the e-mail or return the call as soon as you conveniently can. The trainee is expected to do the same for you. You may find it helpful to look ahead at your schedule when the trainee contacts you each month, and suggest possible times for the trainee's next visit.
3. **Follow your trainee until the end of the academic year:** Your trainee is scheduled to begin his/her Family Mentoring Experience in October 2004 and complete it in June 2005. We ask that you stay with the program until then. If something unforeseen happens that makes it too difficult to continue in the program, please discuss it with the Parent Coordinator. If we cannot work something out, your trainee will be assigned to another family.
4. **Sharing your life experiences with the trainee:** It is important for your trainee to see the many aspects of raising a child with special needs. Sometimes families feel they must "put on a happy face" for the trainee, but that limits what the trainee learns from you. For that reason, we ask that you please share both the good times and the bad times with your trainee. This will help the trainee be a better professional in the future when working with families of children with disabilities.

Roles of Family and Trainee

- In the Family Mentoring Experience, YOU are the teacher.
- You are the expert on your child. You have a wealth of information and experience as a family with special needs, and there is much that the trainee can learn from you that he/she may never have the chance to learn in the normal course of professional practice.
- The trainee is the student. He/she is not acting in a professional capacity. For this reason, we request that you not ask your trainee for professional services such as therapy or medical advice.

In order to best educate your trainee, please take some time to think about the following questions:

1. What would you like a professional to know about your family and your family's life? You may wish to cover topics such as:

- When and how you found out about your child's special needs
- What services you have used or are using now for your child
- Scheduling and coordinating medical care, therapy, child care, etc.
- Ways that you have found professionals to be helpful and not so helpful
- The joys and challenges of everyday life
- How your child's disability has affected:
 - relationships within the family and with friends and beyond
 - your other children, if you have others
 - how you use your time, money, energy
 - your ability to plan ahead
 - your leisure time
 - your ability or need to work
 - your feelings about the future
- Your source of strength
- Anything else you would like your trainee to learn from you and your family

2. What do you want your trainee to experience or see with your family?

- If mealtime is an adventure in your house, invite your trainee to experience it with you.
- If your child's evening routine is always a challenge, invite your trainee to spend that stretch of time with you one night.
- You might wish to invite your trainee to an I.E.P. meeting at your child's school.
- Other suggestions:
 - observing your child in school
 - attending a therapy session
 - playing with your child on the playground
 - watching your child in a recreation class or on a sports team
 - attending your child's birthday party
 - shopping for groceries or gifts

These are just a few suggestions. Consider what would best help the trainee get to know YOUR family.

Checklist for First Visit or Call

- Exchange phone numbers and any alternative contacts if appropriate (work number, cell phone, pager, e-mail, etc.) Discuss the best ways to reach each other.

- Share good and bad times to call. For example, you may want to let your trainee know when bedtime is at your house so they don't call at that time.
- Negotiate timing and frequency of contacts. We require the trainee spend a minimum of 20 hours with your family. They are not, however, permitted to baby-sit or provide childcare for your family during the period of the Family Mentoring Experience.
- Share any household rules that your trainee needs to know about.
- Discuss parking and safety issues if necessary.
- The first visit: Introduce your trainee to everyone in your family, if possible. If you are a two-parent household, it is important that both parents be involved in the Family Mentoring Experience with your trainee. You may want to talk with the trainee alone to give some family history and details of your child's disability and related issues, and then have the trainee spend some time with your child(ren). The trainee will be sensitive to the importance of not discussing such issues as diagnostic labels, adoption, etc. in front of your child(ren).
- Set the date, time and place for your next visit and write it on your calendar. You may want to discuss possible activities for future visits.

Confidentiality

It is important for you to be open with your trainee so he/she can truly see what it is like to have a child with a disability. Trainees have been instructed to always maintain your confidentiality so that you can be comfortable sharing your life with them. They will be writing in a journal and sharing some of their insights and experiences with the other trainees and faculty in the LEND program. In this capacity, they are to use first names only of children and only non-identifying words such as "dad", "mom", "grandma", etc, when referring to adults. They are required to write and speak in a respectful manner that protects your confidentiality. They are never to discuss their mentoring family in a public place or with people who are not in the program. They may not give any information, such as your place of employment or name of your child's school that might make it easy to identify you. The trainees are, however, required by law to report any abuse and neglect.

Program Evaluation

We will be evaluating the FME and the trainees throughout the academic year. Success of the program will be based on the following:

- Journal kept by trainee with observations and reflections on their Family Mentoring Experience. This is a private journal kept by the trainee for his or her own growth as a professional. It will not leave the medical center. It will not be included in your child's medical record, but will be treated in the same confidential manner as a medical record. The journal is read only by the trainee's faculty advisor, the Training Department director, and the Parent Coordinator in

order to give the trainee feedback on his/her participation in the Family Mentoring Experience.

- Quarterly group meetings for trainees and faculty. These meetings provide the opportunity for our trainees to learn from one another and learn about families beyond their own mentoring family.
- Occasional phone calls to families from Parent Coordinator
- End-of-year evaluation of the program by families via a questionnaire
- End-of-year evaluation of the program by trainees

On-going Support

It is the responsibility of the Parent Coordinator, Sheryl Feuer, to make sure the mentoring experience is a positive one for both the families and the trainees. Sheryl will be contacting you periodically to ask how your mentoring is going. You are always welcome to call or e-mail Sheryl if you have questions or concerns at any time during the year. She can be reached at work at **636-4626**, at home at **522-7155**, by cell phone at **513-508-9586**, or by e-mail at sheryl.feuer@cchmc.org. Please do not hesitate to call her at any time!

We look forward to working with you this year, and all of us in the LEND program hope that you and your family will find the Family Mentoring Experience interesting and rewarding. Thank you for volunteering for this important program and helping to build better, more family-centered systems of health care!

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