

*Promising Practices
in Family Mentorship:
A Guidebook for
MCHB-LEND
Training Programs*

_____, 2006



Promising Practices in Family Mentorship: A Guidebook for MCH-LEND Training Programs

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 - i. Supervision from and reporting to LEND Director and/or Training Coordinator
 - ii. Extent of full/shared responsibility and authority for the Family Mentorship program, including recruiting/selecting/orienting families, matching families and trainees, orienting trainees, monitoring FM process, bringing FM to a close, coordinating evaluations, collecting/reporting/analyzing data, and using data to improve FM design for the following year
 - iii. Coordination with faculty advisors and other faculty as appropriate before, during, and after implementation of the Family Mentorship (encouraging faculty to incorporate trainee FM experiences in other parts of the curriculum, conferring to develop plans to deal with unexpected contingencies, etc.)
 - iv. Other roles in LEND/UCEDD (advisory group, committees, etc., if any)
 - b. Selecting the FM Coordinator
 - i. Identify current position linked to family aspects of LEND which could logically be expanded to include coordinating FM;
or

- ii. Convene a search committee to:
 - 1. Develop position title and description
 - 2. Establish training and life experience criteria
 - 3. Identify preferred personal and professional qualities
 - 4. Post position and conduct interviews
- c. Selecting the FM Coordinator and orienting her/him to roles and relationships

3. Identifying Outcomes for Trainees and Families

- a. Establishing outcome expectations for trainees linked to LEND competencies
- b. Developing FM learning objectives for trainees
- c. Looking ahead to developing evaluation materials and procedures (Chapter 10)

4. Developing the FM Design: Visits and Add-On Components

- a. Overview of LEND FM designs
- b. Designing the specifics for trainee/family visits (number, duration, etc.)
- c. Selecting and designing add-on components
- d. Considering alternative FM options based on a trainee's previous experiences
- e. Other aspects to consider in FM design
- f. Contingency and liability planning
- g. Looking ahead to developing orientation materials/procedures for families and for trainees (Chapters 6 & 7)
- h. Looking ahead to developing evaluation materials/processes for families and for trainees (Chapter 10)
- i. Looking ahead to be ready to use evaluation feedback (Chapter 11)
- j. Importance of keeping detailed schedule and records at every phase

5. Recruiting and Selecting Mentoring Families

- a. Recruiting families
 - i. Decide if families will be volunteers or receive a payment for their service as mentors
 - ii. Develop a description of other potential benefits and outcomes for mentoring families
 - iii. Develop outreach strategies to potential family resources and networks
 - iv. Design outreach materials/documents
- b. Selecting families
 - i. Establish family selection criteria
 - ii. Establish family selection process
 - iii. Develop a standard procedure for notifying selected families of their selection
 - iv. Develop family information or registration materials such as pre-matching questionnaires
 - v. Establish a process for confirming the family's ability to commit to the completion of the FM for the designated academic period

- vi. Establish policy/procedures to follow in the case that you recruit a family for whom FM is not appropriate, keeping in mind that families may be offended if they are not selected after demonstrating interest
 - 1. Include statement that there may not be sufficient trainees for all willing families
 - 2. May include statement about alternate (indirect) opportunities for families to participate in LEND
 - 3. Keep a list of families and the most appropriate ways each might contribute to LEND training (FM home visits, presenting in classes, etc.)
- c. Implementing recruitment and selection of mentoring families
- d. Evaluating recruitment and selection phase

6. Orienting Families to the Family Mentorship

- a. Designing materials and procedures for family orientation
- b. Developing a process for notifying families about details of their matches with trainees
- c. Implementing orientation of families
- d. Evaluating family orientation phase

7. Orienting Trainees to the Family Mentorship

- a. Developing pre-match forms and procedures for trainees
- b. Gathering trainee's information to use for matching
- c. Designing an orientation process for trainees using applicable materials
Trainee orientation may include information on:
 - i. The purpose of Family Mentorship: what it is and is not
 - ii. How trainees will be matched with mentoring families
 - iii. Details about any group scheduled events
 - iv. Instructions and guidelines for scheduling and conducting individual visits and any other interactions with matched families between visits
 - v. Samples of materials provided to mentoring families
 - vi. Requirements and expectations for the successful completion of the FM experience
 - vii. Related and post-visit assignments
 - viii. Support available from FM Coordinator/faculty/staff including how to address unexpected problems or challenges with family matches
 - ix. Evaluation process
 - x. Expressing appreciation to mentoring family and other follow-up activities
- d. Conducting a trainee orientation
- e. Evaluating the trainee orientation phase

8. Matching Trainees and Families

- a. Developing matching criteria (for assigning a particular trainee to a particular mentoring family), materials, processes, and contingency plans
- b. Identifying preliminary matches, using pre-match information from families (chapter 6) and trainees (chapter 7)
- c. Revising matching system/matches as needed based on contingencies that may have arisen, and then finalizing matches
- d. Implementing the matching process with trainees and families (notifying them by mail or email, holding a families/trainees group meeting, etc.)
- e. Evaluating the matching phase

9. Coordinating the FM Once It's in Process

- a. Maintaining ongoing communication and relationships with trainees
- b. Maintaining ongoing communication and relationships with families, as appropriate
- c. Coordinating FM required activities, including coordinating with faculty advisors or other faculty/staff as appropriate
- d. Tweaking and troubleshooting during the FM period
- e. Evaluating this phase

10. Bringing Closure to the Family Mentorship

- a. Developing closure/evaluation methods including:
 - i. Trainee/family closure process, to be initiated by trainee
 - ii. FM Coordinator/families closure process, including evaluation materials and thanks/stipend if promised
 - iii. FM Coordinator/trainees closure process, including evaluation materials as appropriate and grading if appropriate
 - iv. Planning trainees/families group closure activities, if desired
- b. Implementing all of the above closure and evaluation activities
- c. Providing feedback to trainees and/or families after or as part of the evaluation process

11. Using Evaluation Data to Modify FM Design

- a. Making changes during the process based on feedback at every phase
- b. Planning changes for next year
- c. Incorporating questions about Family Mentorship in protocols for LEND trainee exit interviews
- d. Considering adding Family Mentorship-specific questions to long-term trainee follow-up surveys

12. Ideas for Linking FM with Other Aspects of the LEND Program and Beyond

- a. Related faculty roles
- b. Related family roles in clinical settings, interdisciplinary teams, etc.
- c. Links to other UCEDD programs, Title V programs, clinic networks, etc.

13. Summary

- a. Hope this has been helpful
- b. Review key principles and themes from Introduction
- c. Point reader to the Appendices
- d. Suggest adaptability of the FM model for use in other training or practice/service contexts

Feedback Form

Appendix A – Sample Family Mentorship Documents from LEND Programs

Appendix B – Sample Family Mentorship Documents from Similar Programs

Appendix C – General Disability Resources on Family Issues

Appendix D – T/A Directory for LEND Family Mentorships

Preface

Family Mentorship is only one of many ways to incorporate the real life experience and expertise of families into professional training programs; but Family Mentorship has proven such an effective teaching/learning experience in LEND programs that we are devoting this entire Guidebook to it. Family Mentorship is a discrete component of a professional training program whereby families act as teachers, or mentors, to trainees, and trainees learn from families through visits with them and through related learning experiences. In the model presented in this Guidebook, trainees are matched with families who have children with disabilities or special health care needs, and the trainees have the valuable opportunity to get to know and appreciate the families as PEOPLE, not as clients or patients. Family Mentorship provides the kind of person-to-person real-life sharing of experiences that no textbook or classroom lecture can offer – and which too many professionals are missing in their education and experience.

There are as many ways to “do” Family Mentorship as there are programs doing it. At the same time, all Family Mentorship programs are built using the same basic building blocks. We have tried in this Guidebook to represent the wide range of possibilities within each of the main components of any Family Mentorship. The Guidebook content reflects promising practices in Family Mentorship which have been developed by LEND programs across the country and found to be effective and beneficial for their trainees and families. There is no “ideal” way to do Family Mentorship, because every Family Mentorship program is customized to fit its given setting, and every setting is unique. Keep this in mind as you read, and select or adapt the materials that seem the best fit for your own training program.

There is also no prescribed way to use this Guidebook. We have tried to organize the content in the same general order in which LEND Family Mentorship programs typically proceed. For each phase, planning and document design generally occur before the phase is implemented -- for example, it’s helpful to develop a plan and recruitment materials before you actually begin to recruit mentoring families. Once each phase is completed, it can be evaluated and changes can be planned for that phase of the next Family Mentorship cycle (usually the next academic year). We have integrated planning, implementing, and evaluating within each chapter, for purposes of organizing the content. But this is not to say that these steps always follow in the exact order in which we have listed them! A LEND program just beginning a Family Mentorship may need to do a great deal of the program planning and document design for all phases of the Family Mentorship first, before taking a single step towards actual implementation of the very first phase. A LEND program with an existing Family Mentorship will already have FM plans, procedures, and documents in place, and its FM coordinator may well be “doing” the steps of FM in whatever order they may be needed – for example, coordinating the FM in process while recruiting families year-round while using evaluation data to tweak orientation materials and procedures. Such a LEND program may look to this Guide merely for new ideas to enhance its Family Mentorship.

Based on all the materials and input we have received from LEND programs across the country, the basic building blocks that Family Mentorship programs have in common are:

- Defining the role of the FM Coordinator and selecting that individual
- Identifying outcomes for trainees and families
- Developing the Family Mentorship design (visits and additional components)
- Recruiting and selecting mentoring families
- Orienting families
- Orienting trainees
- Matching trainees and families
- Coordinating the Family Mentorship during its duration
- Bringing closure to the Family Mentorship
- Using evaluation data to modify FM design

Each of these topics has its own chapter in this Guidebook. We have tried to keep the format user-friendly and practical, incorporating within each chapter both an overview of that topic and a checklist of related activities.

In addition, we include in Chapter 1 some elements and themes which we consider absolutely fundamental to Family Mentorship as an effective family-centered training experience within LEND programs. We also include a chapter offering suggestions for linking Family Mentorship with other aspects of the LEND program and beyond it. The Summary chapter points to the adaptability of the LEND Family Mentorship model to other professional training programs and to practice/service settings which could benefit from intentionally involving persons with disabilities of all ages and their families as mentors to trainees, professionals, or staff. And we include four appendices to jump-start the reader's efforts to begin or enhance a Family Mentorship:

- **Appendix A** contains a great number and variety of Family Mentorship documents in use by LEND programs.
- **Appendix B** includes some materials about and from Family Mentorships as implemented in some other, similar training programs across the country.
- **Appendix C** contains a variety of resources on “family and disability” that LEND Family Mentorship Coordinators have found useful for trainees and professionals working with mentoring families and/or other families of children with disabilities or special health care needs.
- **Appendix D** is a technical assistance listing of Family Mentorship Coordinators at LEND programs across the country.

Family Mentorship is an excellent training model for promoting effective and caring family-professional collaboration. We sincerely hope that you find this Guidebook practical and user-friendly as you seek to begin or enhance a Family Mentorship program. Please let us know how helpful and easy to use you find this Guidebook, and share your comments and suggestions by completing the form at the end of the Guidebook. We wish you much enjoyment in creating or enhancing your Family Mentorship program and in reaping the rewards to trainees, families, and your LEND program as a whole.

Chapter 1: Introduction

“I don't think we were implementing or providing training in family centered care until we included family members as faculty and family mentor experiences in our training program.

“It is essential for trainees to understand families as people with individual needs that go beyond just their medical needs.

“There is no more effective way of teaching these issues than by utilizing family mentors. The LEND programs are now leaders in this area thanks to their family faculty and mentors.”

Mark L. Wolraich, MD
Oklahoma LEND Director,
Developmental & Behavioral Pediatrics,
CMRI Shaun Walters Endowed Chair

The definition of Family Mentorship is the matching of trainees with families of a person with a disability and the activities and learning experiences associated with the match and visits. (Crystal Pariseau)

Purpose: “The purpose of the Family Mentor Program is for trainees to increase their appreciation of what it is like to have a child with special needs.”

58 Excerpt WI MCH LEND 2005-2006 FAMILY MENTOR GOALS

Compelling Value of a Family Mentorship

Family Mentorship emphasizes the complementary expertise of families and professionals by opening the window into the everyday lives of families and their commitment to full and productive as well as healthy lives. It balances a professional's scientific, clinical, and condition-specific knowledge of disability and health with a family's holistic, practical, and family-centered approach. Insights gained from families about their goals, factors in decision-making or priority-setting, and the value placed on each family member are beneficial in understanding how to work effectively with families. The opportunity to develop skills in working with families as partners is anticipated to impact future practice that is more meaningful and effective for both families and professionals.

In addition to this broad-based understanding of “who a child is,” a parent also possesses a very detailed and specific body of knowledge about a child's medical condition. Over time, many parents have become experts at managing complex medical needs in the home and in the community. Furthermore, as long-term and frequent consumers of

health care services, parents are a wealth of information regarding the design and delivery of those services. (Vermont #55)

This guidebook is focused on *Family Mentorship*, but there are many roles families can and should play in the development of future leaders. From co-teaching and lecturing, serving on panels, and course design and evaluation, to being interdisciplinary team members in clinics, families are key partners and need and desire to be included. Family members of children with disabilities possess an area of expertise equally as important to the interdisciplinary team process as the professional's area of expertise. The family's expertise is gained over time through the experience of living with the person with developmental disabilities. There is no didactic experience sufficient to replace the reality of a family experience!

As each LEND reflects the unique differences of the area in which it is located, each family mentorship program is different. Across the network family mentorship matches may occur on a one-to-one basis or at a different ratio for a more interdisciplinary experience. Many family mentorship contacts occur in person, while others occur via telephone, written or virtual (internet) connections. In one program the family mentorship experience entails a trainee meeting the family at home or in the community, and in another a trainee may accompany a family to clinic appointments. Some family mentorship experiences last as few as 8 hours over the course of an academic year, others as long as 40 hours. This guidebook contains many of the promising practices in family mentorship from the 35 LEND programs existing in 2006.

The following guidebook is intended to be used as a compendium of experiences and possibilities for you to choose from when creating or enhancing a family mentorship program at your LEND program. The appendices and the compilations of materials within designated chapters are from LEND programs across the nation. We urge you to utilize the body of the guidebook as a step-by-step tool and also to take advantage of the additional sections filled with materials that can be used in a variety of ways to expand and enhance the inclusion of families in your respective LEND programs.

Key Elements and Themes in Family Mentorship

Although each LEND program differs somewhat in teaching and practice and trainee composition each year, there are four key elements which are federally mandated for every LEND program. Those key elements are:

Leadership
Interdisciplinary Personnel Preparation
Family Centered, Inclusive Practices and Services
Culturally Competent and Sensitive Services

Leadership: Leadership training prepares MCH health care professionals to move beyond excellent clinical practice to leadership through research, teaching, administration and advocacy. LEND trainees should be prepared through their education and experience to “influence others in their attainment of a common goal.”

“Advancing the knowledge and skills of the full range of child health professionals to:
1) improve health care delivery systems for children with developmental disabilities

- 2) providing high-quality education and training for health professionals
 - 3) providing a wide range of health professionals with the skills needed to foster a community-based partnership of health resources and community leadership
 - 4) promoting innovative practice models that enhance cultural competency, partnerships between disciplines and family-centered approaches to care”
- (LEND Brochure, page 3)

Interdisciplinary Personnel Preparation: meaning trainees in disciplines such as pediatrics, nursing, social work, nutrition, speech-language pathology, audiology, pediatric dentistry, psychology, occupational therapy, physical therapy, health administration, genetics, special education, and parents of children with disabilities work as a team to address the needs of children and families

Family Centered, Inclusive Practices and Services: assures the health and well-being of children and their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions and expertise that everyone brings to this relationship. Family-centered care is the standard of practice that results in high-quality services.

In July of 2005, The Maternal and Child Health Bureau, Division of Services for Children with Special Health Needs, disseminated the new definition of Family Centered Care including an explanation of the role of cultural competence and a letter of introduction, history and explanation from Merle McPherson (see appendices #). We want to include the new definition to illustrate The Bureau’s continued commitment to the inclusion of families and the importance of families being involved in the personnel preparation of health care providers through mentoring programs. The foundation of family-centered care is the partnership between families and professionals.

“Family-Centered Care assures the health and well-being of children and their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions and expertise that everyone brings to this relationship. Family-Centered Care is the standard of practice which results in high quality services.” (The Maternal and Child Health Bureau, Division of Services for Children with Special Health Needs)

Culturally Competent and Sensitive Services: is defined as a set of values, behaviors, attitudes, and practices within a system, organization, or program or among individuals that enables them to work effectively cross-culturally. It refers to the ability to honor and respect the beliefs, language, inter-personal styles and behaviors of individuals and families receiving services, as well as staff who are providing such services. At a systems, organizational, or program level, cultural competence requires a comprehensive and coordinated plan that includes interventions at all the levels from policy-making to the individual, and is a dynamic, ongoing, process that requires a long-term commitment. A component of cultural competence is linguistic competence, the capacity of an organization and its personnel to communicate effectively and convey information in a manner that is easily understood by diverse audiences including persons of limited English proficiency, those who are not literate or have low literacy skills, and individuals with disabilities. (The Maternal and Child Health Bureau, Division of Services for Children with Special Health Needs)

Beyond these four key elements, we are suggesting that four additional themes are fundamental to any Family Mentorship, for they provide additional opportunities for mentors and trainees to enrich and be enriched in their practice and scholarship. They are:

People First Language
Life Span Perspective
Inclusion of Sibling Issues
Considering the Family's Experience as a "Discipline"

People First Language: The guiding principle for non-handicapping language is to maintain the integrity of the individuals as whole human beings by avoiding language that (a) implies that a person as a whole is disabled (e.g., disabled person); (b) equates persons with their condition (e.g., epileptics); (c) has superfluous, negative overtones (e.g., stroke victim); or (d) is regarded as a slur (e.g., cripple).

"For decades, persons with disabilities have been identified by their disability first, and as persons second. Often, persons with disabilities are viewed as been afflicted with, or being victims of, a disability. In focusing on the disability, an individual's strengths, abilities, skills, and resources are often ignored. In many instances, persons with disabilities are viewed neither as having the capacity or right to express their goals and preferences nor as being resourceful and contributing members of society." (*Excerpt from "People First Language," The American Psychological Association, copyright 2003*)

Lifespan Perspective: Children with disabilities grow up! It is important to include the opinions, participation and body of work that adults with disabilities contribute to the training of service providers. When it comes to "outcomes," adults with disabilities are the experts. We must only look at the current position of and opportunities for adults with disabilities in the community to understand the importance of training that incorporates the AUCD/LEND principles. Families and adults with disabilities challenge us to look at practices, policies and interventions that they deem appropriate and beneficial life-long.

The following are some of the topics in which the *Lifespan Perspective* can be explored by recruiting family mentors who have adult children with disabilities and by inviting adults with disabilities to be part of the discussions: Person Centered Services, Self-Directed Services, Dollar-Follows Funding, Olmstead Decision, Community Based Waiver Services, and Long Term Care.

Sibling Issues:

"Currently 526,000 Americans with disabilities are 60 years or older and that number is expected to triple – to over 1.5 million – by 2030 (National Center for Family Support, 2000). Given that 60% of these adults are cared for by aging parents in the family home, who will take care of them when their parents no longer can? Adult siblings of adults with disabilities are the assumed future caregivers, but the needs of adult siblings have remained relatively unexplored." (*"Siblings of Persons with Disabilities: Toward a Research Agenda," Vol. 43, Number 5:334-338 AAMR*)

Additional emphasis on siblings, their relationship to their brother/sister with a disability, and their access to supports in childhood and throughout life are very much a part of family-centered practice and also contribute to the lifespan perspective of

children/adults with disabilities. The lifespan issues of siblings include disability information/understanding, peer relationships, family role, responsibilities, aging, and caregiver/non caregiver choices. Recruitment of a Family Mentor who is an adult sibling is another opportunity for your LEND program.

Considering the Family’s Experience as a “Discipline”: From the AUCD/LEND perspective, which is training diverse interdisciplinary personnel to work with families and their children with disabilities, it can be helpful to describe the information and expertise held by families by describing what the family knows and has experienced, as their “*discipline.*” (OK LEND) Considering the family’s expertise as a “discipline” similar to the academic discipline areas of education, physical therapy, speech-language pathology, etc., recognizes the importance of the family’s contribution to the interdisciplinary team.

“The family ‘discipline’ includes information about the child/family member with a disability that is inherent to his/her own family, acquired by life experiences, and affected by the culture and community in which the family lives. It is essential information that the family shares with professionals to ensure access to individualized supports and services.” (*OK Center for Learning and Leadership 1995 article, “Family as a Discipline,” TASH conference*)

This concept is currently being incorporated into the curriculum and materials of a growing number of LEND programs. It has potential for enriching and broadening the much wider range of training programs for all those disciplines in which family-professional collaboration is fundamental to practice and service.

Benefits to Trainees From a Family Mentorship Experience

“This was one of the best aspects of my LEND training. I feel that I have learned more from talking with and watching my family than from any class I have taken. It allowed me to appreciate the real concerns families have with the care for their child and the day-to-day issues that come up. I have also learned about how raising a child with special needs can be a very warming and positive experience.” – trainee 2004

“It helps bring everything into perspective.” – trainee 2005

“Hearing parents’ perspective of interactions with health care workers will change how I treat families in the future. I have learned the importance of taking time with the families and treating them with respect.” – trainee 2005

Family Mentorship provides the opportunity for trainees to learn:

- A family is the sum of *all* of its members, including those in the extended family.
- All families have strengths.
- Families are diverse: each family is different, and no two children with the same type of disabilities are alike.
- Family-to-family communication and support is important.
- Children with disabilities and their families live most of their lives on their own turf in their home and community, outside of clinical settings.
- Families wish to collaborate and partner with health care professionals.

- Family participation is a contribution from the families that better prepares our trainees to work with families post-LEND.
(summarized from #23 & 15 Cincinnati, Ohio, #7 Westchester NY, #4 & 5 Iowa)

Achieving the practice of “Family-Centered Care” means future professionals must have real opportunities to be mentored by families. It is our hope that the suggestions and documents, tools and examples furnished in this tool-kit developed by Family Faculty members across the nation will assist you in your efforts to develop and enhance the Family Mentorship component of your LEND Program.