

# Promising Practices

## IN FAMILY MENTORSHIP

PATIENCE  
Care  
Commitment  
MENTOR  
Giving  
Love  
TRUST  
Sharing  
WARMTH  
Laughter  
Family  
HONESTY  
Happiness  
CHERISH



# *Promising Practices*

## IN FAMILY MENTORSHIP

**A Guidebook for MCHB-LEND Training Programs**

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**Association of University Centers on Disabilities**

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*Those* of us who worked on this Guidebook receive constant inspiration from the people we love. To them and to all the families who participate in our LEND programs we dedicate this Guidebook.



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and the numerous contributions of faculty, staff, Family Mentorship Coordinators, mentoring families, and trainees from the nation's LEND programs.

*The authors would like to express our deep gratitude to our editor Crystal Pariseau for her belief in the merit and value of Family Mentorship and the importance of developing and disseminating this Guidebook. We extend special thanks for her patience, willingness, and skill as our point-person and editor, as well as for her commitment, encouragement, and support in seeing this project come to fruition.*

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The LEND section of [www.aucd.org](http://www.aucd.org)





# PREFACE

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In February 2005 the Maternal Child Health Bureau (MCHB) of the U.S. Health Resources and Services Administration (HRSA), and the Association of University Centers on Disabilities (AUCD) sponsored a meeting on family involvement for the MCHB-Leadership Education in Neurodevelopmental Disabilities (LEND) programs<sup>1</sup>. Fifty faculty and staff from around the country attended this meeting and discussed the Maternal Child Health (MCH) philosophies of family involvement in training programs, training in family issues, and the utilization of the family experience and perspective in training curricula.

LEND programs provide long-term interdisciplinary leadership training to graduate-level health professionals at universities and schools of medicine around the country. In LEND, long-term trainees are those who complete 300+ hours in the MCHB LEND leadership training program. The purpose of LEND programs is to improve the health of infants, children, and adolescents who have or are at risk for developing neurodevelopmental and other related disabilities by preparing trainees from a wide variety of professional disciplines to assume leadership roles and to ensure high levels of interdisciplinary clinical competence.<sup>2</sup>

The objectives of the LEND program are to:

- 1) advance the knowledge and skills of the full range of child health professionals to improve health care delivery systems for children with developmental disabilities;
- 2) provide high-quality interdisciplinary education to health professionals which emphasizes the integration of services supported by States, local agencies, organizations, private providers and communities;
- 3) provide a wide range of health professionals with the skills needed to foster a community-based partnership of health resources and community leadership; and
- 4) promote innovative practice models that enhance cultural competency, partnerships among disciplines, and family-centered approaches to care.<sup>3</sup>

To address these objectives, in particular number four, a workgroup of Family Meeting attendees was formed to create a guidebook for use by LEND programs and any MCHB training program that wants to integrate a family mentorship experience.

This guidebook is based on the work done by faculty and staff at LEND programs across the country, many of whom are family members of children or adults with disabilities.

The nation's LEND programs are funded by HRSA's MCHB.

LEND programs are members of AUCD, a 501(c)3 national association. In addition to the LENDs, AUCD counts as its members the nation's 67 University Centers for Excellence in Developmental Disabilities (UCEDDs) funded by the Administration on Children and Family's Administration on Developmental Disabilities (ADD) and the 19 Developmental Disabilities Research Centers (DDRCs) funded by the National Institute of Child Health and Human Development (NICHD). AUCD provides a national network and technical assistance to help UCEDDs, DDRCs and LENDs carry out their missions.

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<sup>1</sup> In FY2005 35 LENDs were funded by MCHB in 28 states and the District of Columbia. For a current listing of all LEND programs and their contact information, please visit [www.aucd.org](http://www.aucd.org) and click on LEND.

<sup>2</sup> HRSA-06-048 program guidance: Maternal and child leadership education in neurodevelopmental and other related disabilities. New competitive announcement; fiscal year 2006; release date December 12, 2005. CFDA No.93.110..

<sup>3</sup> Ibid.



# INTRODUCTION

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*Hearing parents' perspectives of interactions with health care workers has changed how I will treat families in the future. I have learned the importance of taking time with the families and treating them with respect.*

~A trainee

Family Mentorship is one way to incorporate the life experience and expertise of families into professional training programs. It offers unique learning and leadership opportunities for LEND trainees. Family Mentorship is a discrete component of a professional training program where families serve as teachers or mentors to trainees through family visits and related training experiences. Many LEND programs find that Family Mentorship is an excellent training model to promote effective and caring family-professional collaborations. This guidebook presents a model in which trainees are matched with families who have children or youth with disabilities or special health care needs. This matching provides the opportunity for trainees to get to know and appreciate the families as PEOPLE, not as clients or patients. Family Mentorship provides the kind of person-to-person sharing of experiences that no textbook or classroom lecture can offer. While this guidebook is designed for use by LEND programs, other professional training programs can easily adapt its content.

There are many ways to provide a Family Mentorship experience for trainees, but they all use the same basic building blocks. The Guidebook presents a wide range of promising practices for each core component of any Family Mentorship program. There is no “ideal” way to do Family Mentorship because each program must be customized to fit its own setting. Readers are encouraged to keep this flexibility in mind and to select or adapt materials that best meet the particular needs of their own training programs and those they ultimately serve.

## ORGANIZATION

The Guidebook is organized as a series of steps that many Family Mentorship programs typically follow. Planning, implementation, and evaluation are integrated into each step, but LENDs may vary their order of these steps. A program just beginning Family Mentorships may need to focus on planning and designing documents for all phases before beginning any implementation. A program with existing Family Mentorships may use this guide as a source for new ideas to enhance or expand its approach.

This guidebook has a chapter on each building block of a Family Mentorship program:

- Principles
- Developing the Family Coordinator position(s)
- Identifying outcomes for trainees and families
- Design
- Recruiting and selecting families
- Orienting participants
- Matching trainees and families
- Ongoing coordination
- Wrapping up

Four appendices provide selected examples and resources from existing Family Mentorship programs:

- 1) Appendix A: Family Mentorship Documents
- 2) Appendix B: Additional References for Family Mentorship programs
- 3) Appendix C: Non-LEND Family Mentorship Programs

4) Appendix D: Technical Assistance Directory for LEND Family Mentorships  
Throughout the guidebook you will see references to documents in these appendices. For example: #1 WI; to view this reference, visit the appendices in the LEND section of [www.aucd.org](http://www.aucd.org) and access the document numbered #1, which is from the Wisconsin LEND.

## TERMS

Each LEND program is different and may use different terminology. In this guidebook we use the following terms:

- *Family Mentorship (FM)* - refers to a specific training component that matches trainees for home and community visits with families who have children or youth with disabilities or special health care needs.
- *Family Mentorship Coordinator* - the faculty member who has primary responsibility for the Family Mentorship, sometimes called “Family Specialist” or “Parent-Family Resources Coordinator.”
- *Mentoring Family* and *Family Mentor* - families participating in the Family Mentorship.
- *LEND Faculty* - staff and or faculty in a LEND program representing a variety of professional disciplines. These staff/faculty might also be referred to as Discipline Coordinators.
- *Family Faculty* – members of the LEND Faculty who represent the “Family” Discipline. Most Family Faculty are persons with disabilities or family members of persons with disabilities.
- *Trainees* – long-term (300+ training hours) graduate students in one of the thirteen MCHB disciplines enrolled in the LEND program.

Documents in the appendices may use variations of these terms.

We published this guidebook as an online document. For those who do not have access to the Internet, a limited number of paper copies are available from AUCD at (301) 588-8252.

We hope this guidebook provides a practical and user-friendly tool for training programs seeking to begin or enhance a Family Mentorship program. We welcome and encourage feedback; please post your thoughts, comments, and questions to the AUCD LEND Family Faculty Message Board in the LEND section of [www.aucd.org](http://www.aucd.org).

*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*

# 1. PRINCIPLES OF FAMILY MENTORSHIP

Family Mentorship can be defined as the matching of trainees with families of persons with disabilities and the activities and learning experiences associated with the matches and subsequent visits.

Inherent in FM are the following:

- The relationship which develops between the trainee and the family;
- The activities and personal perspective the family shares with the trainee;
- Professional development of the trainee gleaned through the mentorship experience;
- A framework to make this experience possible;
- And benefits which vary with program design.<sup>4</sup>

*...the purpose of the Family Mentor program is for trainees to increase their appreciation of what it is like to have a child or youth with special needs.*

(#1 WI)

## VALUE OF A FAMILY MENTORSHIP

*Parents have a unique and valuable perspective, acquired over time, based on countless experiences in a variety of settings. They have a holistic understanding of their child that goes far beyond the details of the diagnosis. While professionals come and go; a parent is there for the long haul and his or her knowledge, insight, and intuition are essential to an effective plan of care... 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.*

(#2 VT)

This guidebook is focused on Family Mentorship, but families can play many roles to help develop future leaders. Families are key partners in co-teaching, lecturing, serving on panels, designing and evaluating courses, and serving as clinical interdisciplinary team members. Family members possess an area of expertise that is vital to the success of the interdisciplinary team's work. The family gains expertise and a unique perspective through the experience of living with the person with developmental disabilities.

As each LEND reflects the unique characteristics of its own area, each FM program is also different. Across the network, FM matches may occur on a one-to-one basis or a different ratio of trainees to families for a more interdisciplinary experience. FM contacts may occur in person, over the telephone or through written or Internet connections. Some FM experiences only last 8 hours over the course of an academic year while others may last up to 40 hours.

<sup>4</sup> The authors adopted this definition for this guidebook. However, since there is no single definition of Family Mentorship, LEND programs are encouraged to modify the definition and the process to best fit their own philosophy.

## KEY ELEMENTS AND THEMES

Every LEND program has four federally mandated key elements<sup>5</sup>:

- 1) Leadership.** Leadership training prepares Maternal Child Health (MCH) health care professionals to move beyond basic 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.”
- 2) Interdisciplinary Training.** Interdisciplinary training means that trainees in many disciplines work as a team with the parents of children or youth with disabilities to address the needs of those children and families. Interdisciplinary teams may include members from 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 and youth with disabilities as well as others.
- 3) Family-Centered Care.** The foundation of family-centered care is the partnership between families and professionals. In July 2005, the MCH Bureau of Division of Services for Children with Special Health Needs disseminated a new definition of family-centered care. This new definition illustrates MCHB’s continued commitment to including families in all aspects of training and practice and the importance of involving families in the personnel preparation of health care providers through mentoring programs:

*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.*<sup>6</sup>

Practicing family-centered care means respecting the family’s expertise as a discipline. MCHB requires that all LEND programs have a member of the family discipline on staff. LEND programs that hold the family’s expertise as a discipline in the same regard as an academic discipline such as education, physical therapy, and speech-language pathology recognize 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.*<sup>7</sup>

A growing number of LEND programs incorporate this concept into their curriculum and materials, and some accept family members as “family discipline” trainees. Viewing “family” as a discipline has the potential to enrich the wide range of MCH training programs for everyone because family-professional collaboration is fundamental to practice and service for children and their families.

- 4) Cultural Competence.** As stated in Goal Two of the MCHB Strategic Plan 2003-2007,<sup>8</sup> LEND training programs include cultural competence training in the curriculum, administrative procedures, faculty and staff development, and recruitment and retention of racially and ethnically diverse faculty and trainees.

*Cultural competence 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...*

<sup>5</sup> LEND competitive grant guidance, 2007-2011. Contact MCHB Training Branch for more information. <https://grants.hrsa.gov>.

<sup>6</sup> [http://www.mchb.hrsa.gov/training/gl\\_familycenteredcare.asp](http://www.mchb.hrsa.gov/training/gl_familycenteredcare.asp). Also see Appendix A, #108.

<sup>7</sup> Center for Interdisciplinary Learning and Leadership/UCEDD/OUHSC (2002), TASH abstract “The Family Discipline”, Francl, C., Moss, J.

<sup>8</sup> <http://mchb.hrsa.gov/about/stratplan03-07.htm>.

LEND programs also address diversity in the workforce by recognizing and stressing the recruitment, advancement, training, and retention of faculty and trainees from diverse backgrounds that are reflective of the nation's diversity and, in particular, of the people they ultimately serve.

In addition to the four key elements described above, three additional themes are recommended for any FM program:

- 1) People First Language.** The guiding principle for people first 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”).

The advantage of people first language is that it shifts the focus away from the disability. This allows a focus on an individual's strengths, abilities, skills, and resources.

*For decades, persons with disabilities have been identified by their disability first, and as persons second. Often, persons with disabilities are viewed as being 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.<sup>9</sup>*

- 2) Lifespan Perspective.** It is important to include the opinions, participation, and body of work that adults with disabilities contribute to the training of service providers. Families and adults with disabilities challenge us to look at practices, policies, and interventions that they believe are appropriate and beneficial life-long. By inviting Family Mentors who have adult children with disabilities and/or who are adults with disabilities to participate, it is possible to explore lifespan topics such as: person-centered services, self-advocacy, self-directed services and supports, community participation, money-follows-the-person funding initiatives, the Olmstead decision, child-youth-adult transitions, community-based waiver services, and long term and end-of-life decisions.
- 3) 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.<sup>10</sup>*

Providing an emphasis on siblings, their relationship to their brother/sister with a disability, and their own access to supports is very much a part of family-centered practice and contributes to the lifespan perspective of children and adults with disabilities. Siblings face lifespan issues such as disability information/understanding, peer relationships, family roles and responsibilities, aging, and caregiver/non-caregiver choices. Recruiting a Family Mentor who is an adult sibling is another opportunity for a LEND program to utilize a family's perspective and expertise.



<sup>9</sup> <http://www.apastyle.org/disabilities.html>.

<sup>10</sup> Robert M. Hodapp, Laraine Masters Glidden and Ann P. Kaiser. 2005: Siblings of Persons With Disabilities: Toward a Research Agenda. *Mental Retardation*: Vol. 43, No. 5, pp. 334–338.



*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.

*~A trainee*

## 2. DEVELOPING THE FAMILY MENTORSHIP COORDINATOR POSITION

Whether starting a new program or looking for ways to enhance an existing one, it is important to consider who have responsibility to plan, implement, and revise the Family Mentorship (FM) program parameters and curriculum. Key attributes of successful FM programs include designating staff time and having clearly articulated support from Directors and faculty, and having one or more individuals who can focus attention to coordinate the work of trainees, Family Mentors, and family faculty.



A LEND program may employ an FM Coordinator full-time, part-time, or as a consultant. The coordination role may be only one of multiple functions, the sole responsibility for a staff member, or shared by two or more people. Most programs find that the coordination role does not require advanced academic, clinical, or professional credentials. They report that the most important attributes are positive communication skills, the ability to organize and follow through with recommendations, and a commitment to the core values of LEND. Many FM Coordinators are parents or family members of people with disabilities or chronic health conditions. A parent or family member serving in the Coordinator role exemplifies the LEND program's commitment to family-centered care and emphasizes the complementary expertise of parents or family members and faculty with academic appointments. The FM Coordinator can also provide a connection to families in the community, family organizations, and parent leaders. Personnel and budget allocation varies from program to program due to the scope of activities, personnel guidelines, individual skill or qualifications, and overall budget priorities. Budget decisions and allocations, though important, are not discussed in this guidebook.

FM programs frequently start from humble beginnings and grow as budgets and faculty allow. This Guidebook is a compilation of ideas and suggestions from many LEND FM programs, some which are well-established and others which are in the early stages of development. No FM is doing all of the possibilities included in this Guidebook, and none of them emerged fully-developed in their first year. The FM program can begin simply at first, for example with a single family visiting with trainees in a class setting. Over time and with increases in budget and resources, the FM design can grow toward more involved and more personalized contacts in community locations and family homes, and additional learning opportunities can be built into the FM framework.

### DEFINING ROLES AND RESPONSIBILITIES

Clear expectations and supports for the FM Coordinator greatly contribute to an effective and sustainable program. While each LEND program may have its own approach to defining the role and developing a description of responsibilities, these questions may help begin the process:

- What are the needs and preferences of the program and stakeholders? (Stakeholders might include trainees, families, faculty, funders, or others)
- Who will provide supervision and support to the Coordinator?
- How will FM Coordinator(s) interact with program faculty, families, trainees, and community organizations?
- What supports and structure do trainees need from the Coordinator?
- What supports and structure do families who will serve as Mentors need?
- What specific activities will fall within the scope of coordination?
- What legal or programmatic guidelines must each individual FM program address? Examples include HIPAA, confidentiality, mandatory reporting of abuse or neglect, risk management, and activity reporting.

Position Descriptions of some LEND Family Mentorship Coordinators are included in Appendix A, (#3 VA and #4 WI).

## CHARACTERISTICS AND QUALIFICATIONS

Key characteristics of an FM Coordinator are good communication and time management and organizational skills. The life experiences of family members or parents often make these people ideally suited to the role and provide a powerful linkage between the LEND program and families who are living with the joys and the challenges of their children or youth with disabilities or chronic health care needs.

It is often said that families must recognize their own strengths and needs in order to work effectively with other families who are facing challenges. This concept of “putting on your own oxygen mask first” also applies to FM Coordinators. Difficult situations experienced by families and the tough ethical, moral, and legal questions that trainees may encounter in their visits with families require maturity and an ability to reflect with skill and thoughtfulness.

Examples of qualifications for the FM Coordinator role include:

- Experience as a family member or parent of a child with special needs
- Strong interest in family-centered care and family leadership
- The ability to articulate their family/self-advocate experience to various audiences
- The ability to work collaboratively as a team member
- Experience and sensitivity working with diverse families and professionals
- Positive communication skills, including clear written and oral communication skills
- Public speaking skills
- Strong computer skills to use email, word processing, spreadsheet and database software
- Time management skills and the ability to work independently (#5 OK)

Experience in parent-to parent supports or ties to a local parent organization may also be helpful for the FM Coordinator.

## STRUCTURING A POSITION

The duties of an FM Coordinator may require less than a full-time position, but often require flexibility in workspace, hours, and supports. Since many FM Coordinators are parents, job sharing may offer the advantage of having back-up when family circumstances require temporary absence. Job sharing can also provide mutual support from other families working in academic or clinical settings. FM Coordinators should have flexible schedules in order to work with families, Family Mentors, and trainees whose schedules may preclude contact during regular business hours.

Many coordination duties might be completed through telephone or email contact and by connecting with families and organizations in the community. Some FM Coordinators can work successfully from home.

Programs should consider alternative ways to utilize the expertise of family leaders who serve as FM Coordinators. It may be easier to recruit and retain Faculty in the Family discipline who have other roles within the LEND program. Expanded responsibilities benefit both the program and those family leaders who seek professional employment. Examples include:

- Oregon Institute on Disability and Development, Oregon LEND: The FM Coordinator and Family Discipline/Training Coordinator share responsibilities to recruit and support Family Mentors. They also serve as consultants with the Family Involvement Network of Oregon’s Title V program.
- Center for Learning and Leadership (Oklahoma) and WIHD (Westchester, New York): Family faculty members who coordinate the FM program teach portions of the LEND curriculum on family-centered care, family supports, and self-determination. Some Family faculty also supervise LEND Family trainees, coordinate other LEND leadership projects, and provide support to families in clinical settings.

- Partnership for People with Disabilities, Virginia LEND: The FM Coordinator participates in monthly clinics; co-leads class sessions; coordinates a session on issues around chronic illness, death, and grief; compiles information on special education/disability law; and attends UCEDD events and LEND faculty meetings.

## ORIENTATION AND SUPPORT

In order to provide opportunities for trainees, Training Coordinators, Discipline Coordinators, and the FM Coordinator need to develop a trusting relationship and a comfortable learning environment. It may be helpful to consider providing the following as part of the FM Coordinator orientation:

- Overview the LEND program goals and curriculum;
- Description of how the FM experience relates to other objectives and activities of the curriculum;
- Personal introductions among all Discipline Coordinators, support staff, and trainees; and
- Requirements and schedules of trainees that might affect LEND activities.

The FM Coordinator should be fully included in the annual LEND trainee orientation. For example, he/she may help faculty plan the event, provide a presentation about the FM experience, and have time to socialize with trainees. When trainees meet the FM Coordinator and other Discipline Coordinators on their first day, they receive a clear message that the FM Coordinator is a full and integral partner of the LEND faculty.

The FM Coordinator may need administrative and technical supports. It is important to identify who will provide the necessary assistance. This may include instructions on how to operate electronic equipment (computers, PDA devices, office and cellular telephones, etc.).

Providing opportunities for the FM Coordinator to assume additional leadership roles or to receive academic training shows support for the position and also benefits the LEND program. Ideas to consider include: attending or presenting at national meetings (e.g., AUCD, AMCHP, or TASH) and assuming a leadership role within organizations (e.g., Developmental Disabilities Council, Parent Training and Information Centers, chapters of United Cerebral Palsy, Down Syndrome associations, or The Arc).

## RELATIONSHIP WITH DIRECTORS AND DISCIPLINE COORDINATORS

In most LEND programs, the FM Coordinator is accountable to the Training or LEND Director. Providing opportunities for periodic check-in and problem-solving helps assure progress and quality. New FM Coordinators may benefit from frequent feedback from Directors, faculty, and other Family faculty. Participation in regular LEND faculty meetings and on committees (e.g., the LEND's Training Advisory Committee, Training Coordinators Council, or Curriculum Development Committees) also enhances the relationship with the faculty and encourages communication and collaboration among the Discipline Coordinators, the trainees, and the FM Coordinator.

The LEND Directors, Training Directors, and other faculty help set the tone and priority for the FM experience. Positive communication among the faculty and trainees shows support for the Coordinator and enhances the potential success of the FM experience.

*Knowing that the professionals in the LEND program cared enough to become personally involved in my family's ongoing struggles for acceptance in our community, obtaining appropriate education for my children with special needs, and locating quality medical care provided a much-needed impetus for me to continue the battle for what my children need and deserve.*

*~A mentoring parent*



## 3. IDENTIFYING OUTCOMES FOR TRAINEES AND FAMILIES

*Nothing can replace a sustained reflective engagement with a family in our training in childhood neurodevelopmental disabilities. 'Riding the bus' of daily living with our mentoring families helps the trainees enhance their perspectives and get out of their professional-only 'box.' The impact of public policies, resource allocation, geography, curb cuts, and a world of other issues becomes a personal story that the trainee shares. It helps the LEND graduate be a more grounded leader.*

*~Joann Bodurtha, MD, MPH, Director, VA-LEND program,  
Partnership for People with Disabilities,  
Virginia Commonwealth University*

Family Mentorship (FM) planning begins with identifying outcomes and benefits for both trainees and mentoring families. Careful planning maximizes the opportunities for achievement of program goals.

### OUTCOMES FOR TRAINEES

FM supports the overarching goal of LEND programs: leadership development of trainees. Trainees learn how to be leaders within their respective disciplines and become equipped to bring to their professions a deep appreciation of the lives and needs of families. They also learn the value of practicing in interdisciplinary, family-centered, culturally competent ways to meet the needs of families.

FM gives trainees an opportunity to learn directly from families about life with a child who has a disability, through visits with the family over a specified time period. While the FM is organized to encourage and guide this learning by trainees, it is ultimately up to the trainee to invest the time, energy, and interest to maximize this learning opportunity. FM provides an opportunity for trainees to learn:

- All families have strengths
- A family is the sum of all of its members, including those in the extended family
- Families are diverse: each family is different and no two children with the same type of disabilities is alike.
- Family-to-family communication and support are important
- Children and youth with disabilities and their families live most of their lives on their own turf in their home and community, outside of clinical settings
- Families generally want to collaborate and partner with health care professionals.
- Family participation is a contribution from the families that better prepares trainees to work with families post-LEND
- Family centered care is built upon family–professional collaboration.



## OUTCOMES FOR FAMILIES

The FM experience holds great potential for beneficial outcomes for mentoring families as well as for trainees. Most mentoring families greatly appreciate the opportunity to contribute personally to the training of professionals who will work with families like their own. They often treasure the opportunity to share their families' stories and lives with trainees who are caring, knowledgeable, and attentive listeners. Through the trainees and the FM Coordinator, families are given a personal link to the wider LEND program, its resources, and its expertise. Other outcomes for families will vary widely but often include assistance with respite, advocacy, or other services; opportunities to network with other families; access to resources, information or LEND presentations; and opportunities to share their experience and expertise with audiences beyond their own matched trainee and opportunities to learn new leadership and other important skills.

Beyond the intended outcomes of any given FM, there may be additional outcomes such as friendships between trainees and mentoring families, enrichment of the LEND curriculum as a whole, greater community awareness of LEND and UCEDD resources, and much more. FM provides the opportunity for families to do the following:

- Gain personal satisfaction by contributing their expertise to the education and preparation of future service providers
- Tell their story in a learning environment outside of a clinical setting
- Demonstrate that services or recommendations that may appear critically important from a professional perspective can decrease in importance when viewed within the context of the family's daily routine
- State their choices and priorities in a safe environment and be listened to
- Build collaborative partnerships with future professionals. (Adapted from #6 NM)

*My family's participation in LEND Family Mentorship has provided rewards I didn't initially expect. I felt confident that our trainee would benefit from the realities of our family experiences. But I didn't realize that I would be making valuable contacts for many years to come. I have always been sad to see our family's trainees finish their program and move on. But it is indeed comforting to know that those same trainees will now better understand what all families like mine need and want.*

*~A mentoring parent*

## ESTABLISHING OUTCOME EXPECTATIONS

The FM Coordinator can establish outcome expectations by working with other LEND faculty to:

- Review the established competency goals for the LEND program and prepare a set of FM learning objectives that are linked to them
- Establish criteria for trainees' successful completion of the FM, including both learning objectives and activity requirements
- Determine specifics about activities to be included, including visits with mentoring families and supplemental activities
- Establish a way for the Coordinator to stay informed of trainees' progress and families' experiences and feelings as they participate
- Prepare evaluation materials for completion by trainees and mentoring families and plan procedures for wrapping up the FM relationship
- Establish a plan for the evaluation of trainees by faculty (FM Coordinator and/or faculty advisor) including grades, if applicable

- Incorporate questions about outcomes in existing protocols for LEND trainee exit interviews and follow-up surveys
- Establish a system of annual review of learning objectives and activities using data from all available sources
- Identify additional ways in which Family Mentors or other appropriate families can be included in the general LEND curriculum and activities
- Consider ways to broaden the involvement of families in the LEND curriculum by developing linkages with schools and departments within the University, family groups, advocacy organizations, and community and governmental agencies.

**FM LEARNING OBJECTIVES**

The learning objectives of any FM can serve as a guide for its design and should be clearly linked to the LEND program competency goals. Learning objectives may differ widely among programs depending on the specifics of the design and whether trainees are encouraged to identify personal FM goals and activities. Whether identified by the program or by the trainee, learning objectives should be incorporated into FM evaluation materials. In one example, the WIHD (Westchester New York) LEND evaluation process asks families to complete a form rating the LEND trainee on items such as: (#7 NYW)

	Always	Almost Always	Infrequently	Never
1. Used “People-First Language” in talking about our child(ren). For example: “our child with autism” rather than “our autistic child.”				
8. Made comments supporting the notion that good parent/professional collaboration is important.				
9. Was easily accessible and responded in a reasonable amount of time to schedule and complete the visits.				

Following are two examples of FM learning objectives from the Strong Center for Developmental Disabilities LEND in Rochester, NY and from the WIHD LEND in Westchester, NY. Additional examples can be found in Appendix A. (#8 & #9 WI, #10 VA, #11 OHC, and #12 VT).





### Learning Goals for LEND Trainees

- 1) To understand the impact a child with developmental disabilities and special health care needs may have on the entire family.
- 2) To learn about the emotions experienced and stages of adjustment parents go through when a child is diagnosed with a developmental disability or special health care need requiring ongoing care.
- 3) To appreciate the value of good collaboration between parents and professionals.
- 4) To learn about community resources available for children with special needs and their families.
- 5) To consider obstacles, challenges, opportunities and outcomes of school and community inclusion for children with developmental disabilities or special health care needs.
- 6) To understand the importance of family-centered practices.
- 7) To increase awareness of how personal attitudes and biases can impact upon a professional's relationship with children with developmental disabilities and special health care needs and their families including issues of a philosophical, emotional or ethical nature.
- 8) To increase appreciation of the potential, capabilities, and contributions of children and youth with developmental disabilities. (#13 NYW)

### Objectives

After participating in the practicum, fellows [trainees] will be able to:

- Develop a strength-based empowerment orientation in working with families
- Demonstrate an increased understanding of daily issues faced by families
- Articulate an understanding of families' experiences accessing systems and resources
- Appreciate the information, resources, and support families gain from each other
- Articulate their attitudes regarding families who have a member with a disability and reflect critically about them in the context of society's stigma toward people with disabilities.

(#14 NYS)

*I learned what families value. I feel fortunate to have been provided with the unique opportunity of being included in a family with a child with special needs. I better understand the life of this family. I thank them and you so much for this opportunity!*  
 ~A former trainee

## 4. DESIGNING A FAMILY MENTORSHIP PROGRAM

The essence of Family Mentorship is the opportunity for trainees to spend time interacting with a family who has a member with a disability or special health care needs. The premise is that trainees will learn first-hand about the family's life, not as patients or clients, but as people. The foundation of FM is visits between trainees and mentoring families, including visit-related activities and orientation, implementation, and evaluation materials.

In addition, many LEND programs incorporate activities to supplement family visits. These activities integrate the FM more fully into the larger LEND curriculum and encourage trainees to process their experiences with their mentoring families and broaden their learning about families. Supplemental activities vary widely and range from items like trainee journals to major projects on behalf of or with their mentoring families.

All FM programs share basic elements that include:

- Family Mentorship Designs
  - Trainee-Family Visits
  - Supplemental Activities
  - Considering Alternative Options
  - Additional Design Considerations
- Formative and Summative Evaluation

It is important to remember that FM should fit into the broader curriculum. Each FM is unique and can be customized to fit the needs of the trainees, mentoring families, and training curriculum. The visits and supplemental activities shape and are shaped by the outcome expectations and learning objectives.

The process of designing visits and supplemental activities also involves decisions about other elements of FM, such as:

- Recruiting and selecting mentoring families;
- Designing orientation and materials for families and trainees;
- Designing match criteria and procedures;
- Planning how the Coordinator will stay in touch with trainees and families;
- Developing methods and materials for wrap-up and evaluation; and
- Using evaluation data and the reflection outcomes to modify the design.

*I have to say the LEND experience has been one of the most valuable experiences I had in school to prepare me for the work I am passionate about, which is helping families who have children with special needs. I use everything I can remember from the LEND experience and wish I could remember even more from it. It is so much great information, that I couldn't take it all in at that time. For me, the families put a personal face on the information and that's why I found the mentoring and family presentations to be so valuable. I always felt it takes a lot for a family to share their life and story with students who are strangers to them. I applaud those who can do it because I sincerely think it makes a difference.*

*~A former trainee*

There is a wide variety of FM designs across the LEND network. Each LEND determines its own design and how many hours will be devoted to it. There is no one right way to design a FM program. All FMs include visits as the core of their FM, though the approaches vary widely. Across the network, FM matches may occur on a one-to-one basis or a different ratio of trainees to families for a more interdisciplinary experience. Most programs have supplemental activities, which also vary. Several examples of FM design are included in the chart on the next page and others can be found in Appendix A (#12 VT, #16 CA, #17 OHC, and #18 NYW).

*This* experience allowed an inside look at what it is like to raise the children whom we simply work with a few hours a week. These families are extraordinary in their sacrifices and needs, and learning from them through the family mentorship program was an invaluable tool in my clinical training.

~A former trainee



*LEND long-term trainees and fellows are required to participate in a 'family mentor experience,' which provides them with an opportunity to learn directly from a family. Working with a family allows trainees/fellows to acquire an appreciation for what it means to raise a child with special needs at home. Through a variety of experiences with the family, trainees and fellows will gain knowledge about social, environmental, medical, and health service systems and the responsiveness of the systems, other family members, and the community to children with special needs and their families.*

~MIND program, Nashville, TN (#15 TNN)

**FM DESIGN EXAMPLES**

<i>LEND Program</i>					
<b>The CHILD Center, California “A Day in the Life”</b>	<b>Iowa LEND, Parents as Mentors (PAM) program</b>	<b>Center for Disability and Development, New Mexico LEND Family Faculty program</b>	<b>Center for Learning and Leadership Oklahoma LEND, Family Mentorship</b>	<b>Virginia LEND, Family Mentorship Experience</b>	<b>Waisman Center, Wisconsin LEND Family Mentor program</b>
<i>Visit Requirements</i>					
8 hours.	4 visits during the first semester.	First semester: minimum 8 hours; second semester: minimum 16 hours.	At least 1 meeting with each family per academic year; approximately 6-8 meetings total.	5 substantive visits per academic year.	20 hours of visits October - April. Orientation & Get-Together group activity.
<i>Features</i>					
Trainees are responsible for identifying families to be their mentors. They then interview the family to obtain a sense of daily life. Trainees have one home visit and one community-based visit with their families.	Mentoring families receive materials to help them decide what they would like to share with their trainee. Trainees complete a pre- and post-FM self-assessment on family-centered care.	Trainees complete a project for the family, which must be done in an area outside the trainee’s own discipline. Mentoring families receive a \$300 stipend.	Trainees visit with a series of Community Faculty (CF), chosen based on their leadership roles within the state’s disability community. Each CF has a network of families in their organization.	Visits are conducted in a variety of home and community settings, including a get-to-know-you picnic and end-of-year picnic. Trainees stay in touch with their families between visits with telephone calls or emails.	Based on the MCHB family-centered care competencies, trainees develop goals for the FM and families share what they want to teach trainees. Visits take place in the home and in a variety of clinical and community settings.
<i>Supplemental Activities</i>					
Trainees keep a journal and submit a short paper about their mentorship experience, including personal reactions and reflections.	Semester 1: Trainees document visits and write a final reflection paper. Semester 2: Trainees identify a policy or systems change based upon the first semester’s learning, explore the issue, share findings with the family, and document their findings in a final paper.	Trainees get to know their mentoring families in the first semester. In the second semester, trainees contract with their families to plan and complete a supplemental practica project that meets a need identified by the family. Trainees keep a year-long journal and write a final paper.	Each family mentor organizes for trainees an experience that they believe is essential for future professionals OR the family arranges for the trainee(s) to shadow them on a specific venture to experience the family perspective.	Trainees keep a journal; attend a training session on chronic illness, death, and grieving; attend group discussion meetings; participate in web-based discussions; and plan a closing picnic for trainees and families.	A discussion group question is posed on-line at Learn@UW and trainees participate in a Family Perspectives group dialogue. Trainees are encouraged to re-visit what family centered care means to them as they gain exposure & insight to the perspectives of their mentoring family.

## TRAINEE-FAMILY VISITS

These are helpful questions to consider when planning the FM visits:

- What are the objectives for having a family mentorship?
- How many hours will trainees devote to the FM?
- When during the academic year will the FM take place?
- What training will the mentoring families receive?
- Will trainees be matched with and visit families alone, in pairs, or as a group?
- What criteria will the program use to match trainees with mentoring families?
- Where will the trainees visit with their mentoring families? Is the variety of locations selected by the FM Coordinator or chosen by the family and the trainee together?
- How will trainees and families first meet?
- Are trainees and families encouraged to make additional contacts between visits to maintain and foster the relationship?
- What resources are available to mentoring families if they have questions or conflicts?
- What are the requirements for trainees to complete the FM successfully?
- How will the families provide feedback to the FM Coordinator or LEND faculty on the program and the trainee(s)?
- Are the mentoring families compensated for their participation? If so, how?

It is likely that every FM design will change over time to meet different circumstances and incorporate new opportunities.

## SUPPLEMENTAL ACTIVITIES FOR THE FAMILY MENTORSHIP

Supplemental activities in FM serve to deepen the trainees' learning experiences by providing the following opportunities to:

- Help trainees reflect on what they are learning in their home or community visits
- Encourage trainees to incorporate their FM experiences into the broader LEND curriculum
- Give mentoring families opportunities to share their experiences and expertise at classes or seminars
- Offer trainees training on specific family issues
- Provide a service or product to the mentoring family or LEND program
- Provide a group learning experience for trainees and mentoring families together

Common FM supplemental activities include journals or portfolios, discussions, additional training sessions, social activities, projects, presentations, or any such combination. Information on these activities follows.

### Family Mentorship Journal or Portfolio

Some LEND FM programs utilize a journal or portfolio activity to supplement the family visits. For example:

#### LEND Family Mentoring Journal Entry: September

##### What did you do?

I had dinner and played with the girls, Briley and Rose.

##### Who or what made an impression on you and why?

Ryan (dad) did – he made a huge Tupperware container with beans and peas – it was the perfect b-day gift for Briley and I was impressed that he tailored it to meet Briley's sensory needs. It shows again that parents are truly the experts. The gift is something I would use as a future O.T.

**What surprised you?**

I asked about a mouthing issue that I noticed at Briley's daycare last week. She tends to mouth her fingers a lot—I hadn't noticed this at home on my first visit and am curious if it's mainly a daycare occurrence or I just didn't notice it before. Dad said Briley does it out of over stimulation (for comfort) or boredom.

**What did you wonder about?**

After her parents confirmed my observations at school I am really interested in watching an O.T. session at school and seeing what they are working on with Briley.

**What challenged you?**

It was challenging to answer her parents when they asked me what I thought about Briley and daycare and my experience. I didn't want to emphasize the bad or the good too much and it was hard to put into words how I felt she did. She does o.k. socially, but seems more comfortable in certain instances than others ("running time" vs. free play).

**What barriers did you perceive?**

This isn't a barrier that I perceived today, but I had seen it at school yesterday and hearing her dad's (Ryan's) thoughts on it really struck me. Ryan brought up the fact that Briley's day care is very into self-direction and Briley doesn't do well with this. Briley was sitting on the couch in a circle and her teacher was going around asking who wanted to play in what area. The kids were supposed to raise their hands if they wanted to do an activity. But Briley didn't raise her hand – perhaps out of not comprehending or out of a lack of ability to communicate. So she was assigned to the last activity but it was clearly not what she wanted to do. It's a hard position—I am sure on one hand, the teachers may feel that if they accommodate her too much all the other children will want the same, but it was hard since the whole point is about choice and she didn't get any say in that instance.

**What did you do that you felt good about?**

Call me crazy but I was holding Briley up on my lap and she arched back and hit me squarely on the nose with her head. Her mom, Tonya, said that it meant I was "officially part of the family, now that I've been 'bopped in the head' by Briley."

**What worried you?**

Nothing specific. It was troubling to see that her parents had the same frustration I did with the smock incident. (At daycare yesterday, she wanted to play in the water area, but refused to wear a smock because she doesn't like tight things around her neck. So she was not allowed to play there.) But her father had the idea to buy her a light raincoat or wind-breaker for her to wear so it was rewarding to see that her parents are so concerned about her participation and are really on top of what's going on.

## Individual or Group Discussions

The FM Coordinator, faculty advisor, or other faculty should be available to trainees during the FM for consultation, both in group or classroom settings and for individual appointments as needed. Group discussions either in-person or on-line may help trainees share and learn from their FM experiences. These discussions may also include the families so trainees and families can learn from one another in a different setting.

## Additional Training Sessions

It may be useful to offer additional training to trainees in topics that are not extensively covered elsewhere in the LEND curriculum. For example, topics may include promising practices in family-centered care, service coordination, advocacy, life transitions, person-centered planning, special education law, Medicaid waivers, or legal/ethical issues. In one example, the Virginia LEND requires that trainees participate in a single-session training on chronic illness, death and grief as part of the family mentorship experience (#10 VA). Faculty, mentoring family members, or former LEND trainees may present the topic's material and facilitate a group discussion. Mentoring family members enjoy the opportunity to share their life experiences and expertise as an additional training session. It may be useful to ask families to participate in a training session as a group, which provides the chance to meet one another and share information about resources, advocacy, networking and support groups for families of children or youth with disabilities or special health care needs. The Oklahoma LEND has a protocol for inviting family members to speak to a class which contains suggestions for helping family members prepare for the presentation, whether they are accomplished public speakers or presenting for the first time (#24 OK). In such instances, it is important to consider giving the family member payment or an honorarium sufficient to express appreciation for the individual's time and expertise as well as to cover mileage, parking fees, and the cost of child care.<sup>11</sup>

## Group Social Activities



There is often a distinct need for group social activities that do not include discussion groups or trainings. Family members' ages, interests, and abilities will span a very wide range, so the activity should be something that all can enjoy. An indoor picnic with play space for the kids, an outdoor picnic near an accessible playground or open play space, a free musical performance or sports event, or a holiday production with donated tickets can be fun for families and still be valuable learning experiences for trainees. It is worth a little extra work to find ways to offer the activity at no cost to families. Location, full accessibility and food are important considerations – collect dietary limitations when planning a menu. These group social activities can be used at any point in an FM program: as an introductory orientation (#25 WI), a mid-year holiday event, or a goodbye event, as detailed here with an invitation to a farewell party for the Wisconsin LEND Family Mentor participants (#26 WI and see also #27 NM).

## Trainee Project

Trainee projects are customized assignments designed to benefit the LEND program or meet a need identified by the mentoring family. If families are asked to identify the need, it can be helpful to offer them brief descriptions of previous trainee projects to provide some ideas.

- Projects may benefit the LEND program
  - Research a topic of interest to families and compile a resource packet for the LEND library
- Projects may be done with or benefit the mentoring family
  - Conduct an advocacy project
  - Provide child care/respite care for the family. (Note: It is important to check the program/university's liability policies before deciding if this is appropriate)
  - Connect the family/youth with organizations or groups that they might find helpful or fun

<sup>11</sup> If you have questions like these, consider submitting the topic to the LEND Family Faculty listserve/message board at <http://www.aucd.org/mb/index.cfm?which=lend!>

- Make a videotape of a child who is transitioning to a new program to assist the providers in the new environment. Create an “all about me” book for a child’s transition to a new school
  - Create a scrapbook with the family of the child’s first years or put together a DVD with and for a family who has adopted children or youth with disabilities and has not had time to organize and enjoy their photos and family stories
  - Assist a family to grocery shop and prepare a meal or help a teenager who loves cooking shows to plan, shop for, cook, and serve a dinner for her entire family
  - Provide one-to-one attention to the sibling of a child with multiple needs
  - Assist the family in daily routines and chores
  - Research eligibility for services, programs, or entitlement benefits such as SSI, Medicaid, etc.
  - Locate and summarize information about a rare genetic disorder
  - Help to locate respite/childcare providers
  - Create a record-keeping book for a child who has multiple medical and therapy providers
  - Reorganize the bedroom of a child who has a visual disability to give the child greater independence in dressing and other activities
- (#6 NM plus additional ideas from NM LEND)



### Trainee Presentation

A presentation serves as a leadership and learning opportunity both for the trainee who prepares and delivers the presentation and the audience. Some examples include:

- Research and present on a topic of interest to other trainees and/or families.
- Make a presentation based on the trainee’s own experience as a person with a disability or as a family member of a person with a disability.
- Present on a topic with a family and/or an individual with a disability.

### CONSIDERING ALTERNATIVE FAMILY MENTORSHIP OPTIONS

Trainees come to LEND with a wide variety of backgrounds, including the extent of their experiences with families of children who have disabilities or special health care needs. For some trainees, a LEND program’s “standard” FM may not offer a new learning opportunity. Trainees may have a disability themselves or may have a close family member with a disability. Some trainees may have already worked in the field with a wide variety of families, including experience with families in their homes. For these trainees, the FM program should consider offering other options. A trainee might:

- Serve as an advocate with a particular family to help resolve an important educational, medical, or service issue for the family.
- Prepare a portfolio of personal or family experiences with disability and his/her advocacy efforts to resolve some of the challenges faced.
- Work with a local disability group to help develop resource materials, conduct outreach, or meet some other pressing group need.
- Research a pending local, state, or federal policy or legislative bill to follow its progress, and undertake advocacy efforts in support of or opposition to the policy or draft new legislative language around the chosen topic.



### **Virginia LEND's Alternative Family Mentorship Experience (FME)**

Possible alternatives to the “standard” FME include but are not limited to:

- Pair with a mentoring family which is expert beyond just their own child, so you can focus more specifically on learning more about advocacy and empowerment of families to be leaders.
- Pair with a mentoring family which is in particular need of advocacy and support, so you can focus more on the experience of directly advocating for a family and also more fully appreciate what a family actually experiences in learning to navigate services and systems. Such a family could have been seen in a LEND interdisciplinary clinic or another family identified by LEND.
- If you have a child with a disability, or if you have a disability, you could possibly be a mentoring family for another trainee, but you would still need to work out a plan for yourself for meeting the FME objectives, either through creatively crafting your mentorship of that trainee, through the standard FME commitment and being mentored by another family, or through an alternate option to the FME that you design with faculty...

(Adapted from #28 VA)

## **ADDITIONAL CONSIDERATIONS IN FAMILY MENTORSHIP DESIGN**

### **Participant Observer Role of the Trainee**

The role of the trainee can be enhanced by incorporating the concept of “participant observer,” in which they learn by actively engaging in whatever the family is doing at the time of their visit.

*In doing home visits, trainees may find it helpful to consider themselves ‘participant observers.’ Participant observation is a research tool developed by anthropologists and adopted by researchers in other fields, including sociologists, educators, and medical researchers. A participant observer enters a setting such as a community, a classroom, a neighborhood, or a home to learn from the people who live there. A participant observer aims to become a participant with the people in the setting rather than being just an observer. On a home visit, a trainee enters a family culture seeking to become a participant in that family culture and observe from the perspective of a family member. Participant observation provides a powerful tool for building an understanding of the ways people in different settings experience life.*

*Wording adapted from #19 IA, p. 13*

### **Establishing a Schedule and Record-Keeping System**

Many FM Coordinators have found it useful to establish a schedule and record-keeping system early in the planning. A detailed timeline, schedule, or tickler file can help keep the entire FM on track (#60 VA). The FM Coordinator will need frequent contact with trainees, families, and, at times, faculty advisors and LEND faculty. An effective filing system, whether on paper or electronically, can help organize all the necessary forms,

notes, and documents. The filing system should also track family information such as prospective, present, and past families who have served or may serve as Family Mentors or with the LEND program in another capacity (see Chapter 5).

### **Safety, Contingency, and Liability Planning**

Orientation materials and procedures should address potential concerns that FM Coordinators, trainees and families may encounter during the program. These issues may include:

- Unexpected challenges
  - The mentoring family faces a crisis and drops out of the FM before it is completed
  - The family does not respond to calls or emails over an extended period of time
  - The trainee needs to extend the timeframe
  - The trainee drops out of the LEND program
- Situations of potential liability
  - The trainee wants to transport members of the FM family in his/her own vehicle
  - The trainee wants to provide childcare or respite for the family. (Some LENDs specify that provision of childcare is not permitted, others allow it, and some require it.)
  - The trainee encounters possible abuse or neglect in the mentoring family
  - The trainee feels uneasy and afraid for his/her safety in a visiting situation. As an example, the CCDDBP LEND in Cincinnati, Ohio includes safety information in their FM orientation materials for trainees

#### **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. Although we do not anticipate any problems during your family visits, you should still be prepared for unexpected situations. Familiarize yourself with the “Safety Tips for LEND Trainees on Family Visits.”  
(#29 OHC)

In addition, the LEND’s educational institution may provide general liability insurance for any enrolled student during participation in a required course. The FM Coordinator should determine what such insurance does and does not cover. Trainees who belong to professional organizations that offer malpractice coverage might be encouraged to purchase such coverage.

The FM program is designed within the structure of a University-based LEND training program and operates under the policies and regulations of that University or program. Such policies and regulations typically include:

- Confidentiality: Trainees are expected to practice confidentiality when speaking or writing about their mentoring families. However, there may be occasions during the FM when families and trainees meet together as a group and introduce themselves or wear nametags. It is important to make it clear to families and trainees that outside of these specific events, the practice of confidentiality is essential. Families may say that they do not mind trainees talking or writing about them, but professional ethics dictate that trainees observe full confidentiality in the FM. Trainees should also know the required procedures for confidentiality such as advance photo and video release forms for families to complete.
- HIPAA (Health Information Portability and Accountability Act): One aspect of confidentiality is the protection of families’ personal health information. Trainees may be subject to regulations of HIPAA, federal legislation regarding the use and disclosure of patient health information, and trainee personnel files should contain evidence of HIPAA compliance.

- Prohibited Activities: University or LEND policies may restrict the exchange of money or gifts between trainees and families. FMs should also include a clear statement prohibiting the consumption of alcohol and the use of recreational drugs during visits with mentoring families.

*The design of our LEND Family Mentorship has changed at least a little each year since its inception and a great deal cumulatively during this time. We started out with a mini-version of what our FM has now evolved into, and I know it will be different and even better in years to come. No matter what the FM design has been, every year trainees have reported that they both learned a lot and loved the experience, and every year families have thanked me for this opportunity to get to know and influence a professional who will be working with kids like their own.*

*~an FM Coordinator*



## 5. EVALUATION OF THE FAMILY MENTORSHIP

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Evaluation is a continuous and ongoing feature of a vibrant Family Mentorship (FM) program. In designing or enhancing an FM program, it is important to think ahead to how to evaluate the program's effectiveness in reaching its stated goals. Two kinds of evaluation occur in the course of an FM: formative evaluation and summative evaluation. FM Coordinators should plan ahead to collect and use both kinds of data. In some LEND programs, creating these evaluation tools and collecting data is the responsibility of the FM Coordinator. In others, it is the responsibility of a team of LEND faculty, while other LENDs employ an Evaluation Specialist or Data Coordinator.

### FORMATIVE EVALUATION

After each phase of the FM, it is extremely helpful to review the activities, capture informal feedback, and, if appropriate, solicit formal evaluative data from trainees and families. Formative evaluation may involve asking parents and trainees if they felt an invitation to a holiday get-together provided enough information, or if a campus lecture hall was an appropriate place to have a class discussion. Each FM Coordinator will develop his/her own system to collect and organize this type of evaluative data throughout the duration of the FM.

There are many opportunities for informal evaluation throughout the Family Mentorship which can provide a rich source of ideas to enhance it. Checking in with trainees, families, and faculty can yield suggestions to improve orientation materials, match forms, or FM activities. It is possible to collect informal feedback at any time during the year through group or individual discussions with trainees, mentoring families, faculty advisors, and LEND faculty. In addition, the FM Coordinator can perform his/her own informal evaluation of FM activities and procedures throughout the year and develop ideas for improvements. For example:

- We did not recruit many new families this year. How can we modify our recruitment notices to get a better response?
- What information can we offer to trainees or families who were unable to attend the group orientation?
- What introductory materials will help new families understand the LEND or UCEDD, the FM, and our objectives?

### SUMMATIVE EVALUATION

The formal, or summative, evaluation process generally occurs toward the end of the academic period. However, planning and developing evaluation tools and other data-gathering procedures should occur as a part of the initial planning and development process. For an existing FM program, enhancing the formal evaluation process might mean gathering additional information from former or current trainees, participating families, the FM Coordinator, the LEND faculty, and faculty advisors. A new FM program might develop evaluation tools that allow Family Mentors to evaluate the LEND trainees' interactions with the family and the FM Coordinator to evaluate the experiences of the Family Mentors and LEND trainees.

It is helpful to consider time, effort, interest level, and MCHB grant requirements before developing summative evaluation tools for each group of participants. Among the issues to consider are these:

- Who will design formal evaluation tools? Will mentoring families and trainees participate in the design process?
- Who is the target audience?

- What type of information/data is needed?
- Are participants' responses anonymous?
- When and how will the evaluation tools be distributed?
- What procedures will help to obtain the best response rate?
- Will different evaluation tools be distributed by different faculty?
- What statistical methods will be used to analyze the data?
- Who is responsible for data analysis?
- Will all the evaluation data be compiled into a master report? (#30 and 31 VA) Who will receive a copy of the master report?
- How will results pertinent to the FM be communicated to the Coordinator?
- How much of the evaluation data will be shared with trainees? With families?
- How will the data be used to propose changes to the FM, and who is responsible for proposing and implementing those changes?
- How will the LEND program be impacted by FM evaluation data?
- If changes are recommended, who will make the decisions?

There are a number of evaluation methodologies to consider, including questionnaires sent by email or mail, telephone surveys, personal visits to mentor families, and online survey instruments. When requesting formal evaluations from the Family Mentors, current trainees, or others, it is advisable to include an explanatory cover letter (#17 & #32 OHC). The cover letter, signed by the FM Coordinator, should thank the mentoring family for participating and indicate the purpose of the questionnaire or the agreed upon date for an evaluation interview at their home. If a questionnaire is enclosed, the cover letter should provide a specific return date, the name of a person to contact with questions, and a self-addressed stamped envelope. If the LEND program chooses, sharing anonymous questionnaire results with the Family Mentors can honor their contribution to the FM and may encourage their continued interest in the program.

Formal evaluations may be designed to elicit general feedback about the FM experience, specific components or phases of it, or specific events that occurred during the year. The LEND Training Director may request additional feedback during the trainee's LEND exit interview. By inserting an FM-specific question on AUCD's NIRS (National Information Reporting System) LEND trainee survey, a program can perform a longitudinal analysis on one-, five-, and ten-year post-training follow-up survey data to help determine the program's impact on the careers of former trainees over time.

Depending on the type of formal evaluation tool, results may be qualitative, quantitative, or a combination. Results from the evaluation can help enhance the FM program for the future. Sample evaluation questionnaires and survey forms for trainees, mentoring families, and faculty are included in Appendix A, #33.

### Evaluation by Trainees

This evaluation focuses on the trainee's FM experience and requests feedback on how to improve the FM program. It may consist of:

- Questionnaires or survey tools
- Discussions: in groups, on-line, individually between the trainee, FM Coordinator and/or faculty advisor, or at the LEND exit interview
- A pre- and post-test self-assessment; and/or
- An online longitudinal post-training survey via the AUCD NIRS system.

Examples of questionnaires include:

- Self-Assessment (#19 IA). At the Iowa LEND's Parents As Mentors program, trainees are asked to complete a self-assessment tool to evaluate their progress in achieving the goals of the program. This tool can be used as both a pre- and post-test of the trainee's skills. Questions about the trainee's skills, knowledge, and attitudes are assessed using a 5-point Likert scale and trainees are offered the



opportunity to add narrative comments. Determining whether trainees grow in their skills as a result of the program helps the Iowa LEND make modifications to their FM.

- Student Evaluation of FM Program (#34 WI). At the Waisman Center Wisconsin LEND, trainees complete a student evaluation of the FM program. This questionnaire asks trainees about their learning experiences and challenges as well as their level of satisfaction with supports received from program staff. Trainees are also asked to offer suggestions for both program and staff improvement.

### **Evaluation by the Mentoring Family**

This evaluation focuses on the mentoring family's experience and the trainee's performance. It may request feedback on how to improve the FM and ask families to indicate their willingness to participate again. Evaluations may consist of:

- Questionnaires or survey tools; and/or
- Telephone conversations between the Family Mentor and FM Coordinator.

At the Waisman Center Wisconsin LEND, the mentoring family is asked to evaluate the trainees' knowledge of family-centered care (i.e., use of person first language, listening skills, respect, accessibility, and supportiveness to the family) during his/her interactions with the family (#35 WI).

### **Evaluation by the FM Coordinator**

This evaluation focuses on evaluation of trainees, the appropriateness of the family in the mentoring role, the design of the FM, and the FM program within the LEND program. Evaluations may be formal or informal, based on:

- A review of the results of trainee and family evaluations
- Communication with trainees, families, faculty advisors, and/or LEND faculty during and at the end of the FM
- Evaluation of each trainee by the FM Coordinator and/or other Discipline Coordinator; and/or
- A review of trainee reflections.

At the end of the FM, the FM Coordinator at the Westchester Institute for Human Development LEND rates each trainee's performance on a 0-3 scale (#36 NYW). The evaluation is based on the trainee's FM follow-up group discussion, the trainee's written reflections, and feedback from the mentoring families. The completed evaluation is forwarded to the LEND Director to be used as part of the trainee's overall LEND evaluation.

### **Evaluation by the Faculty Advisors**

This evaluation focuses on both the trainee and the FM program. Evaluations may consist of:

- A review of the results of the trainee and family evaluations
- A review of trainee reflections on FM
- In-person contacts between the Faculty Advisors and the FM Coordinator; and/or
- Discussion of the FM at faculty meetings throughout the year.

### **Evaluation by LEND Faculty**

This evaluation focuses on the FM program as a single program and/or as part of the overall LEND. Evaluations may be based on:

- A review of the results of the trainee and family evaluations; or
- Discussions during faculty meetings or initiated individually as needed.



*Based on evaluation data gathered from families and trainees, informal notes I've taken throughout the year, and the occasional idea that pops into my head, I'm able to assess what has worked and what I wish to adjust or try for the next year. I have also enjoyed hearing from other FM Coordinators how they do things and seeing what I can possibly incorporate in our FM. Part of my personal satisfaction with our FM has come from tweaking and improving it during and after each successive year. Keeping our Family Mentorship new and vibrant every year benefits everyone involved - the trainees, the mentoring families, and our LEND faculty and curriculum - and it gives me new challenges to enjoy each successive year as the FM Coordinator.*

*~an FM Coordinator*

## 6. RECRUITING AND SELECTING MENTORING FAMILIES

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*It was a pleasure to participate in the Family Mentoring program. I am always happy to have professionals who are about to start out tag along with us. I feel it gives them a better picture of reality when they are able to see what our struggles and joys are.*

*~A mentoring family*

*I'd love to be able to do this again. It offers me time to reflect on where we've been from the first day to how far we have come. It provided me the opportunity to take the quiet times to assess where we are as a family and make goals as to the future. I thoroughly enjoyed the LEND fellow; our son did, too. I know we live off the beaten path, but I definitely appreciate the opportunity to work with this program.*

*~A mentoring family*

### RECRUITMENT

Families who have participated in LEND Family Mentorship programs value this important role and describe it as personally gratifying. Testimonials from mentoring families across the country are helpful to recruit prospective families. The cadre of mentoring families can increase each year, building upon families who previously participated and are willing to continue, and adding new ones as well. To provide the broadest spectrum of learning experiences for trainees, recruitment of mentoring families should include targeted outreach to families which reflect the diversity, including disabilities, of the surrounding community.

- *By families:* The FM Coordinator or other staff members can ask parents already involved in LEND or the FM to recruit other families they have met through their children's school programs, community experiences, parent support groups, disability organizations, workshops, family councils, and other networks. Mentoring families can be asked to do direct parent-to-parent recruiting in person, by phone, or by mail or email using recruitment materials provided by the FM Coordinator. Mentoring families are likely to recommend others who would expand the number and diversity of match families.
- *By professional colleagues:* Recruitment should occur on an ongoing basis throughout the year, not just during the few months prior to the start of the academic year. Professional colleagues and the staff at clinical or other settings where family members are present can provide ways to identify prospective mentoring families. Informational flyers can be displayed within the LEND host University, in pediatric offices, clinics, and Children's Hospitals to reach out to prospective mentoring families. Linking recruitment to other activities such as in-service staff training and presentations to health, education and human service professionals may also elicit assistance in recruitment efforts.
- *By former LEND trainees:* Former trainees, especially those from the Family Discipline, may be ideal mentoring families or may recommend others. Programs should consider a way to access information on future mentoring families as part of the LEND trainee follow-up survey or other activities for former



trainees. Additionally, once former trainees complete the training program and become clinicians or community providers, they can help identify appropriate families.

- *By young adults with disabilities and adult siblings of individuals with disabilities and special health care needs:* Given the pediatric focus of the LEND training program, many LEND FM programs look for parents of young children when recruiting mentoring families. Some LENDs also recruit as mentors young adults with disabilities and adult siblings of individuals with disabilities who are serving in a guardianship capacity. This practice reinforces the lifespan perspective promoted by LEND programs and reflects the reality that many adult siblings have parent-like and guardianship roles for their sisters and brothers. Having different adult family members serve as mentors helps achieve greater diversity.

Identifying and recruiting potential family candidates is only the first step. Informal pre-screening, through visits or telephone conversations with prospective families, may determine that some families are not appropriate for a mentoring role, but might share their expertise with the LEND program in other ways. It is also important to track the suitability of current families. The FM Coordinator should ask trainees for feedback and be aware of the family's ability to participate (e.g., Is it limited or problematic? Does the family not have a telephone? Are they experiencing any major crisis?) Because some families may not be appropriate for the FM at one point in time, it is useful to develop policies and procedures for when families may not be selected to participate or to return to the FM program. The experience of some LEND programs indicates that, in the recruitment process, it is useful to acknowledge that the LEND program may not have sufficient trainees for all willing families and describe alternate opportunities for family participation, such as presenting in classes or serving on advisory boards. As previously mentioned, it is important to keep records about all willing families and their participation, including whether a role is appropriate for any given family at any given time.

Regardless of which family members are recruited as mentoring families, it is important to recruit, to the greatest extent possible, a group of families with broad diversity in age, disability and culture.

Each LEND program will have different resources available to recruit mentors. The following are some examples of tools to use when recruiting families:

- Develop a written description of the benefits for participating families. Be sure to include information about whether families have a volunteer role or receive a stipend or other compensation. LEND programs which offer payment to mentoring families currently offer between \$50 and \$500 depending upon the LEND's budget and policy.
- Develop a written description of the expectations for families who participate, including the orientation process, the expected time commitment, types of visiting experiences in the home and/or community, phone or email correspondence between the family and trainee, and supplemental program activities available to the family. The family will benefit from receiving a description of the learning goals for trainees and of how families sharing their personal stories and experience will help trainees develop competence as leaders and practitioners.
- Develop a list of potential outreach activities and approaches including written materials and personal contacts with families. Outreach materials to recruit families might include letters to individual families, printed notices for publication within or as an insert for parent group newsletters, newsletters for colleagues working in clinical or school programs to share with families, or a local newspaper interview. An outreach letter should be brief but include the program's purposes and objectives, the roles for families and trainees, and what trainees are expected to learn. Examples of outreach documents are located in Appendix A and include: #37 TNB, #38 TNB, #39 VA, #40 WI, #41 NYW and #42 NM. Places an FM Coordinator might connect with possible mentor families can include parent workshops, hospitals or clinics, schools, and child play groups.



- With input from faculty, staff, family groups, and networks, the FM Coordinator will develop a list for a recruitment mailing.

## SELECTION

*It is something that is not taught in the classroom. I hope we helped.*  
~A mentoring family

It is helpful to build a pool of mentoring families even if there is no current match for them. With each subsequent academic year and continuous recruitment, the LEND program may identify an ever-larger pool of interested families. This is a good practice because trainees may have specific requests regarding geographic location, diversity, age of the child, or nature of the disability. It is easier to accommodate match requests when there are a greater number of potentially available mentor families.

### Suggestions for Selecting Mentoring Families

- Create a specific family selection process. This may include learning more about families by reviewing information gathered through email correspondence, telephone contacts, and/or face-to-face interviews. The initial contact between the FM Coordinator and the prospective family should discuss the program, clarify the family commitment and program expectations, and answer questions. Once a family indicates interest, the selection process should move as quickly as possible to demonstrate responsiveness.
- Standardize a process and timeframe to notify selected families by email, telephone, or mail. Inform families if they will receive a match at this time or at a later date. Since the status of families changes over time, it is important to re-connect with them before finalizing any match. Both Appendix A documents #43 VA and #44 WI include a sample Family Mentor Roster.
- Create a simple mechanism to stay connected to available mentoring families to maintain their interest and show appreciation for their continuing interest. Keeping in contact with some families for whom there is no current match may create new opportunities to incorporate them in other roles within the LEND program. Examples: inviting families to attend a LEND trainee poster session, sending out fall or spring updates on the FM program, and asking families to participate in other aspects of the LEND program.

*I feel like we are giving everyone a touch of our real world.*  
~A mentoring family

## EVALUATION

It is possible to evaluate the recruitment and selection process in multiple ways. Factors to consider include the number and diversity of mentoring families; effective recruitment strategies; ongoing interest among mentoring families; and feedback from trainees, supervisors, and participating families. This evaluation information will help guide any necessary or desired program changes.

*I feel that the more people that meet kids with special needs, the less problems they will have dealing with them in life. It was a pleasure.*

~A mentoring family



## 7. ORIENTING TRAINEES AND FAMILIES TO THE FAMILY MENTORSHIP

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*I wish I would have had this experience when I was in school. It would have been so helpful to see the 'inside workings' of a child and family to increase our level of understanding and compassion...*  
 ~A mentoring family

The Coordinator should develop a process and materials to introduce trainees and selected families to the Family Mentorship (FM) program. Trainee orientation and family orientation are handled in a wide variety of ways, but all programs share basic common elements: establishing a relationship with the Coordinator, providing materials describing the program and its expectations, and an opportunity to ask questions and clarify roles and responsibilities. As with all aspects of an FM program, planning orientation materials and activities should take into account the unique features and logistics of each LEND program.

Families should receive a set of written orientation materials by mail or email, in person during a scheduled home visit, or at a group orientation. Materials for trainees might be included in the orientation packet which trainees receive on the first day of LEND, distributed during a class session devoted to FM, or shared individually. Some LEND programs schedule an in-person orientation where all the families gather as a group, and some hold a large get-together of families and trainees after matches are made. Any of these formats offer opportunities for trainees and families to review the FM materials and ask questions about the purpose, expectations, and specifics of the program. Following are examples of family and trainee orientation approaches and materials.

### FAMILY ORIENTATION

- At the CCDDBP Cincinnati LEND, the FM Coordinator sends a letter of introduction and appreciation to the recruited family along with a complete family orientation manual (#45 OHC). The letter explains that the FM Coordinator will call soon to schedule a visit to review the enclosed manual with the family. The manual describes the specific objectives, time commitment, and details of the FM program. The family is also told that the trainee will contact them once matches are assigned to arrange the first visit (#17 & #46 OHC).
- At the Iowa LEND, the FM Coordinator sends a parent orientation packet to the family that describes their program from start to finish. It includes a welcome letter, a description of the family role in the Parents as Mentors program, a participation form for the family, examples of what parents can teach trainees, and family and student evaluation forms. A notable difference in this program is that the parent orientation packet includes an assignment letter that already shares with the family who their trainee is and specifies when the trainee will contact the family (#47 IA).
- Another variation is used at the Wisconsin LEND program, which combines family recruitment, selection and orientation into one packet. The packet includes a recruitment letter, a description of the FM program explaining the design, procedures and expectations, and a family information form with a pre-paid return envelope (#1 & #40 WI). In addition to collecting information that will help trainee-family matches, the family information form also asks about interest in other LEND activities that can help trainees learn from families. After matches are made, trainees and families are invited to meet for the first time at a group gathering. The FM Coordinator and other LEND faculty are available to answer questions and ease any initial awkwardness.

## TRAINEE ORIENTATION

- At the Virginia LEND program, the FM Coordinator meets trainees at the LEND orientation. Each trainee fills out a pre-match questionnaire, completes an Alternative FM Options form, and indicates their preferences on a descriptive, non-identifying list of prospective families. The FM Coordinator later reviews this information and all information about available families and then assigns trainee-family matches. Trainees (and families) receive their match information prior to or shortly following a trainee group orientation session. The trainee orientation manual is detailed and includes a form to document family contacts, instructions for navigating the web-based discussion board, and supplemental articles (#10, #28, #43, & #48 VA).
- As part of the orientation at the TIPS for Kids Missouri LEND, trainees receive a detailed description of the purpose, objectives, and requirements of the FM experience. They receive a list of questions to help them reflect upon Family Mentor experiences. In addition, a family visit log is provided so trainees can record their activities with the family and their observations. (#49, #50, & #51 MO)
- Additional examples of trainee orientation materials can be found in Appendix A documents #17 OHC, #18 & #21 NYW, and # 52 NYS.

Following are two tables which contain general checklists that a LEND FM might use when preparing orientation materials for the FM program. The first table addresses orienting families and the second addresses orienting trainees.



*I will encourage the Family Mentor program to families. It is so beneficial for students because they see first hand what it is like to live daily with a child with special needs...I liked the idea that we may have helped to influence a future therapist. Maybe our student will 'relate' more easily to families in the future. Maybe the student will be instrumental in bringing about changes somewhere down the line.*

*~A mentoring family*

## ORIENTING FAMILIES

### *Materials*

- Description of the FM program
- Purpose and philosophy of family mentorship: students learn from families who are the teachers in the interactions
- Goals or learning objectives of the program
- Goals or learning objectives of the individual trainee matched with the family (if matches have already been made)
- Time expectations: the number of visits or hours to expect
- Optional opportunities, if any, such as participation in classes or attending the trainee's graduation
- Timeline: when trainee/family interactions begin and end

### *Expectations*

- Provide families with a clear description of the mentoring process and goals to help ensure a clear understanding of how the visits and interactions might unfold, and, in turn, ensure beneficial outcomes for both the family and the trainee.
- Specify payment, stipend, honorarium, or other compensation (if applicable)
- Specify if families are asked to give evaluative feedback during or at the end of the FM. Describe what they will be asked to evaluate (the program and/or the trainee[s]), the criteria for evaluating, and the process for evaluating

### *Matching Process*

- Honor any specific request made by a family, if possible (for example, to be matched with a trainee in a specific discipline)

### *Contact Process*

- Tell families when to expect a telephone call, letter, or email from the FM Coordinator with information about the trainee, his/her goals, and when to expect the trainee to contact the family

### *Program Guidelines*

- Address the types of interactions and activities through which families can share their lives and expertise with their trainees
- Review common questions trainees may ask of families
- Outline any restrictions on the program or activities, e.g., if families should not expect trainees to provide any professional services

### *Additional Items*

- Review expectations around respite care (if this is part of the FM)
- Review dates of scheduled large group activities
- Share articles or resources of interest to enhance the FM experience of both families and their trainees
- Address expectations of confidentiality: outline how trainees and the program might discuss the family as part of LEND learning classes, but emphasize the family's right to expect confidentiality
- Include tips for families to help visits go smoothly

### *Contact Information*

- Specify whom to contact (FM Coordinator/other LEND faculty/staff) and how to contact them with concerns about support or guidance and to address any problems or issues

<b>ORIENTING TRAINEES</b>	
<i>Materials</i>	
<ul style="list-style-type: none"> <li>○ Description of the FM program</li> <li>○ Purpose and philosophy of family mentorship: students learn from families who are the teachers in the interactions</li> <li>○ Goals or learning objectives of the program and trainees</li> <li>○ Time expectations: number of visits or hours expectations for trainees</li> <li>○ Timeline: when trainee/family interactions begin and end</li> <li>○ Goals or learning objectives of the trainee</li> </ul>	
<i>Expectations</i>	
<ul style="list-style-type: none"> <li>○ Provide trainees with a clear description of the mentoring process and goals to help ensure a clear understanding of how the visits and interactions might unfold, and ensure beneficial outcomes for both the family and the trainee</li> <li>○ Define the requirements and expectations for successful completion of the FM and describe the evaluation and/or grading process</li> <li>○ Emphasize that trainees are not to evaluate or assess the family or to provide any professional services. Their visits are solely for the purpose of learning from the family about their life experiences and issues related to parenting a child with special needs</li> </ul>	
<i>Matching Process</i>	
<ul style="list-style-type: none"> <li>○ Describe how trainees will be matched with their mentoring families</li> <li>○ Include relevant forms or questionnaires to obtain trainee preferences for the match (if appropriate)</li> </ul>	
<i>Contact Process</i>	
<ul style="list-style-type: none"> <li>○ Once matches are made, ask each trainee to review the information and contact the FM Coordinator to confirm that the match will help meet the trainee's learning goals</li> <li>○ Provide each trainee with contact information for their family(s) and a date by which they should make their first contact or visit</li> </ul>	
<i>Program Guidelines</i>	
<ul style="list-style-type: none"> <li>○ Address possible interactions trainees may experience with families</li> <li>○ Review common questions trainees may ask of families</li> <li>○ Clarify instructions and guidelines on how to conduct the visits</li> <li>○ Include any helpful guidance for trainees, such as those in #53 &amp; #54 WI and #19 IA</li> </ul>	
<i>Additional Items</i>	
<ul style="list-style-type: none"> <li>○ Review expectations around respite care (if this is part of the FM)</li> <li>○ Review dates of scheduled large group activities</li> <li>○ Share articles or resources of interest to enhance the FM experience of both trainees and families</li> <li>○ Address expectations of confidentiality and privacy rules. (For an example, see Iowa LEND's Confidentiality and Privacy Oath, #19 IA)</li> <li>○ Share samples of the information provided to mentoring families</li> <li>○ Review safety and etiquette tips for trainees (#29 OHC is one example)</li> <li>○ Instructions and discussion about family-centered care practices and respectful people first language unless this has already been presented and integrated into LEND curriculum</li> <li>○ Review related and post-visiting assignments</li> </ul>	
<i>Contact Information</i>	
<ul style="list-style-type: none"> <li>○ Specify whom to contact (FM Coordinator/other LEND faculty/staff) and how to contact them with concerns about support or guidance and to address any problems or issues</li> </ul>	

## ADDITIONAL ORIENTATION DISCUSSION TOPICS

The FM is a unique social situation for both trainees and families, as professionals-in-training take on the role of learners from families who are experts in their own children. It is often helpful for the FM Coordinator to acknowledge potential trainee-family differences during the orientation process for both trainees and families. Family visits offer a multitude of positive learning experiences, but on occasion, a difficult situation may arise. Every family is unique and any family may at times face complicated daily schedules, unexpected crises, serious illness, or stress from their children's medical or behavioral challenges. If any such circumstance arises, the trainee and/or the family should seek guidance from the FM Coordinator and other appropriate faculty to explore and process the issue.

## EVALUATION

As discussed in the previous chapter, it is helpful to get feedback about the orientation process and the accompanying materials through an evaluation tool or discussion with trainees. The FM Coordinator should also evaluate the effectiveness of the orientation process based on whether it prepared trainees for this learning experience or if they continued to require more information. Family evaluation forms used by LEND programs should specifically ask families if they received enough information about the FM program to prepare them for mentoring (#55 OHC & #56 VA). This can provide valuable feedback on ways to improve the orientation process.







## 8. MATCHING TRAINEES WITH FAMILIES

*What did I learn? What was valuable in my family mentor experience? Joining the family for appointments and soliciting their impressions, feelings, thoughts, helped me to better understand the importance of family-centered care. Also, being with the family during routines—meal prep, riding in the car—helped me see how families with a child with special needs function like other families and how they have different challenges as well.*

*~A former trainee*

The foundation of Family Mentorship (FM) is matching trainees with families so that trainees can gain insight into the perspectives of families caring for children, youth, and/or adults with disabilities. Most FM programs assign matches based on specific criteria, though some make random pairings of trainees with families. Some trainees may request a match with families who have particular experiences and interests, while others may not express any specific preferences. A family might request being matched with a trainee from a specific discipline. Programs might choose to identify matches for the trainee and family or allow trainees to be matched with a family the trainee already knows, though a trainee-family match based on a clinical relationship should be discouraged.

To begin the process, some LENDs find it helpful to collect certain “pre-match” information from both trainees and families. An FM Coordinator might have a conversation with participants or send them a form to gather some or all of the following:

### From trainees

- Contact information: name, discipline, address, all telephone numbers, email address
- Mode of transportation used: car, bus, bike, walking
- Trainee’s level of experience with families or children or youth with disabilities
- Best times to contact the trainee and preferred mode (phone or email)
- Best times for visits in the trainee’s schedule: blocks of time during the day, evenings, and weekends
- Allergies that need special consideration: pets, smoking, etc.

### From families

- Contact information: names, all telephone numbers, home address(es) and email address(es) for parent(s), guardian(s), foster parent(s) or partner(s)
- Children: names, ages, birthdates, schools/school districts attending, and special needs
- Names and relationships of extended family members or others living in the household
- Any schedules, work/school hours, regularly scheduled lessons, therapies, sports, or family interests that may be relevant to the trainee and to FM visits
- Preferred way to be contacted by the trainee: telephone or email
- Best times for family visits with trainee
- Information about pets and smoking (for trainees with allergies)
- Optional (voluntary) information on race, ethnicity, religion, and occupation

*The foundation of Family Mentorship is matching trainees with families so that trainees can gain insight into the perspectives of families caring for children, youth, and/or adults with disabilities.*

- Areas of special interest: school, medical issues, social skills and friendship building, advocacy building, transition and/or job skills, inclusion, behavioral challenges, person-centered planning, or others
- General area of town where family lives and directions to their home or location of first visit

The FM Coordinator may also ask trainees to identify specific learning goals for the experience and ask families what they would like to teach or share with their trainee(s). These questions, along with other suggestions below, can be added to the pre-match forms to provide a better basis for matching trainees and families.

### IDEAS TO CONSIDER FOR MATCH CRITERIA

- Location/geographical proximity
- Ethnic, cultural, or religious backgrounds
- Family composition: single parent, foster parents, domestic partners, families with extended family members, guardians, adoptive parents
- Single child or siblings
- Type of disability
- Age of the family member with a disability: infant, young child, adolescent, adult
- Family interests: specific activities or policy/legislative issues that families may want to teach their trainee(s) or learn more about
- Trainee's previous knowledge of or experience with disability: personal, family, or work experiences
- School district in which the child with a disability goes to school (to avoid potential conflicts of interest by matching a family with a trainee who works in that school district)



This information can be added to a database so that the FM Coordinator can compare trainee information and special match requests. Appendix A documents #43 VA and #44 WI provide examples of how a match request form might look.

The FM Coordinator will notify the families and trainees after matches are made. Each LEND program should select the method and order to collect information, make matches, and orient families and trainees that works best for that program's circumstances.

The FM Coordinator may inform trainees about their family match in a variety of ways, including during a LEND seminar, at a trainee/faculty gathering, during the FM orientation, in a private meeting, or by email. Basic information about the family and directions to the home or meeting site should be included with the match notification. With permission from the families and trainees, some programs share specific information between the match participants. The FM Coordinator may also help start the contact process. Trainees may contact their families directly to set up the first visit or the Coordinator may arrange the first home visit and go along. As an alternative, the FM Coordinator may organize an initial social gathering for all FM participants.

A key element of a LEND program is to develop leadership skills. For trainees, developing relationships with their mentors provides a valuable opportunity to learn communication skills with families. They learn to move past any initial awkwardness, adapt to different personality styles, gain tolerance for others' values, and value the family's expertise and judgment based on their lives with a family member with a disability.

*First of all, we were able to meet one wonderful student. This is the best thing. Second, we felt happy to provide opportunities for this student to become a more caring and knowledgeable professional—a professional who can understand a family's point of view.*

*~A mentoring family*

## 9. COORDINATING THE ONGOING FAMILY MENTORSHIP PROCESS

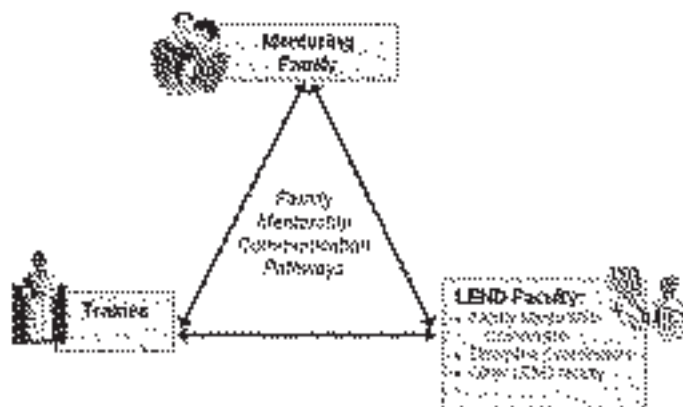
Once the Family Mentorship (FM) is launched, trainees assume primary responsibility for the progress of their relationships with their mentoring families. The FM Coordinator's role may then shift as he/she takes on more managerial tasks. During this period, the Coordinator focuses on communication, ongoing evaluation, and planning, both for wrap-up of the current FM and for the next one. The FM Coordinator may do some or all of the following tasks:

- Stay in contact with trainees and mentoring families to ensure that the FM is going smoothly for each trainee-family pairing.
- Respond to questions or concerns that arise.
- Communicate with other LEND faculty and staff to ensure the FM is integrated into the broader LEND curriculum (i.e., through trainees' discussions of their experiences, involving mentoring families in class presentations, etc.).
- Continue interacting with trainees by participating in classes, clinics, or other aspects of the LEND curriculum.
- Collect and request informal FM evaluative data from all sources.
- Review previous phases of the current FM and keep organized notes to use when improving the next one.
- Plan for the wrap-up phase (see Chapter 10).

### COMMUNICATION

During the Family Mentor program, the family, trainee, and FM Coordinator must all assume responsibility to ensure respectful communication among all participants, as depicted in the diagram below. The trainee takes the lead to communicate with the mentoring family and the FM Coordinator, the mentoring family is responsible to the trainee and the FM Coordinator, and the FM Coordinator facilitates communication among all participants, including Family faculty advisors and LEND faculty. It is important for both trainees and families to know that initiating and maintaining communication in their FM relationship is primarily the responsibility of the trainee.

The following examples, while not exhaustive, are ideas to consider when discussing the communication responsibilities of each participant.



**Mentoring Family communicates with:**

- Trainee:
  - Schedule or change visits
  - Suggest ideas for additional interactions
  - Give updates on family life and issues
- FM Coordinator:
  - Program questions
  - Trainee concerns, if any
  - Life circumstances changes

**Trainee communicates with:**

- Mentoring Family:
  - Schedule or change visits
  - Confirm visits and appointments
  - Share information and resources
  - Schedule email or telephone contacts
  - Make follow-up calls as appropriate
- FM Coordinator:
  - Program questions
  - Mentoring family concerns, if any
  - Schedule contacts, if help is needed
  - Share information and resources from the family
- Family Faculty Advisors/LEND Faculty:
  - Discipline-specific clinical questions
  - Classroom discussions with trainees
  - Professional presentations and projects

**FM Coordinator communicates with:**

- Mentoring Families: The form and nature of these contacts varies between programs. Examples include:
  - Make telephone calls or send emails to check on the FM experience (#57 VA)
  - Address family concerns about the trainee
  - Provide resource materials or emails to families (#58 VA)
  - Offer ongoing support (#45 OHC, #57 VA)
  - Arrange speaking or other opportunities for families in the LEND program
- Trainees:
  - Send reminders of upcoming FM activities and responsibilities
  - Schedule contacts for family visits, if appropriate
  - Address safety issues, as needed
  - Check on the FM experience and problem-solve as needed: Are expectations being met? Are there any concerns?
  - Participate in LEND classes and clinics and encourage trainees to share or draw from their FM experiences in these settings
- Faculty Advisors/LEND Faculty:
  - Invite and encourage faculty to participate in select FM activities
  - Address concerns or issues regarding the FM
  - Address concerns or issues regarding the trainee
  - Integrate FM into other areas of the LEND program

## REVIEW OF THE CURRENT FM PROCESS

Ideally, the FM Coordinator evaluates each phase of the FM as it occurs. However, the initial planning, selection, orientation, and match phases can occur within a fairly short timeframe, so once the trainee-family visits have begun the FM Coordinator may need to spend time reviewing earlier phases and making notes for future reference. Enhancements to the next FM depend in large part on the Coordinator's ongoing evaluation during the current FM program.

## INFORMAL EVALUATION

As previously discussed, the FM Coordinator has many opportunities throughout the year to gather formative (informal) evaluation data. Periodically checking in with participants and actively capturing feedback during conversations and classes are two often-used methods of collecting this valuable input. More information on collecting and using formative and summative evaluation for a LEND's Family Mentorship Program is available in chapter 5.

*I learned that a family knows its child best. Professionals are not the experts, and they may often disrespect the parents and family by trying to be the expert. Also, though families with a child with a disability may have some special issues because of the disability, they are just the same as any other family. Many issues are the same for them as they are for any family. We need to remember that not all challenges are just because of the disability.*

*~A former trainee*





# 10. WRAPPING UP THE FAMILY MENTORSHIP AND PLANNING FOR NEXT YEAR

The ending-time of any Family Mentorship is a distinct phase with specific wrap up and evaluation responsibilities for all participants. The evaluation process needs to focus on collecting data that can help enhance the FM for the following year.

A Family Mentorship program will change over time. Changes may occur for many reasons - new personnel, a shift in curriculum or competencies, or an insight. The FM Coordinator and the LEND faculty and staff need to consider these changes when making deliberate modifications to the FM based on past experience and evaluations.

## WRAP-UP ACTIVITIES

Trainees and mentoring families need to acknowledge the end of their FM relationship. The trainee might recognize the impending end of the FM in a variety of ways:

- Complete a family-related project
- Use the final visit to ask questions, share resources, express appreciation to the family and say good-byes
- Provide the family with a special thank you
- Exchange pictures with the family
- Discuss possible future contact with the family if desired, including the different nature of a future relationship

On behalf of the entire LEND program, the FM Coordinator should acknowledge the end of the Family Mentorship program with the families and show the program's appreciation for their participation. Wrap up tasks for the FM Coordinator may include:

- Solicit summative evaluation information from the families about the program and/or the trainee
- Write, call, or email a thank-you to each family expressing appreciation for their participation
- Inquire about the family's willingness to participate in the next or a future FM
- Send something "extra" (a token gift, an additional resource, etc.)
- Send payment, if this is part of the FM contract with families
- Share feedback from the family's trainee
- Coordinate a closing picnic or social event for families and trainees (#59 VA, #26 WI)

The FM Coordinator will also end the FM with trainees individually or as a group. Examples of such tasks include:

- Review trainee FM journals and/or projects
- Hold a year-end group discussion
- Solicit summative evaluation information from trainees
- Share feedback from the mentoring families

*In #17 OHC, trainees are encouraged to thank their mentoring family for their time and expertise, highlighting some of the meaningful learning experiences. #14 NYS suggests the trainee give the family a video copy of the trainee's formal presentation on their mentorship learning experience or another project to which the family contributed.*



- Say a personal good-bye to each trainee
- Involve trainees in planning a closing picnic or social event for families and trainees

## LOOKING AHEAD

After the FM has ended and the FM Coordinator has brought closure to the experience for both trainees and mentoring families, it is time for the FM Coordinator to think ahead to next year's FM. Thoughtful consideration of data collected from formative and summative evaluation tools, review of accumulated notes, and the benefit of hindsight provide a solid foundation for planning the changes that will result in an effective Family Mentorship for the next year.

*My Family Mentorship experience has really enhanced my professional career. The Family Mentorship experience has given me a unique perspective on the every day challenges families face when they have a child with a disability. This has enabled me to be more empathetic when interacting with the patients that I see in my practice and people I meet in my everyday life. This was an integral and invaluable experience for me and I believe that it has helped to shape my professional view on families with children with disabilities.*  
~A former trainee



# 11. LINKING FAMILY MENTORSHIP WITH THE LEND PROGRAM AND BEYOND

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Beyond a formal program, families of children or youth with disabilities provide mentorship in both subtle ways and obvious ways every day. Mentorship occurs when families participate in typical events without any special accommodations such as going grocery shopping or attending a PTA meeting. It happens when they support other families through organized groups or talk with a “new” family about parenting a child with special needs. Families even mentor professionals by sharing opinions or experiences that influence how professionals may interact in the future. Few service providers forget an emotionally fired or inspirational experience shared with a family of a child with a disability.

This guide is not intended to limit the mentoring experience to a formal model of FM. The following list, while not exhaustive, provides ideas for how families might participate in other aspects of LEND training programs or professional practice and education:

- Families as faculty (adjunct or other)
- Families as LEND project board members
- Families as members of the LEND management team
- Families as co-teachers or co-trainers in courses
- Families as advisors/evaluators/partners in research
- Families as members of interdisciplinary clinical teams
- Families as guest speakers in courses
- Families as reviewers of projects or publication materials
- Families as advisors to tertiary health care operations

There are many examples throughout the LEND network of programs moving beyond an explicit FM program and involving families in their program in creative and innovative ways. A few examples are listed below.

## Center for Medical Home Improvement (CMHI) Parent Partners

- *Building a Medical Home: Improvement Strategies in Primary Care for Children with Special Health Care Needs: Medical Home Improvement Kit (2001)*. This document outlines methods and strategies from numerous medical home initiatives. The information is organized into a comprehensive guide for teams with parents who serve as partners in practice and is available at <http://www.medicalhomeimprovement.org/assets/pdf/MHIK.pdf>. An addendum document is:
- *Parent Partners: Creative Forces on Medical Home Improvement Teams: A Guide for Parent and Practice ‘Partners’ Working to Build Medical Homes for Children with Special Health Care Needs (2003)*. This guide was developed to define and describe the role of the Parent Partner on the Medical Home improvement team. It offers insight into how practices and interested groups can learn about engaging Parent Partners in their efforts to “build” strong Medical Homes. [http://www.medicalhomeimprovement.org/assets/pdf/CMHI\\_PP\\_Guide.pdf](http://www.medicalhomeimprovement.org/assets/pdf/CMHI_PP_Guide.pdf).

## Family Partners Project

- Child Study Center, Oklahoma University Health Sciences Center. <http://devbehavped.s.ouhsc.edu/>. In 2004 the Child Study Center (CSC) began involving family members of children or youth with disabilities in interdisciplinary assessments for developmental disabilities and autism. After the first year of clinics, it became evident that future clinic plans would include family members known as “Family Partners.” The CSC adapted the above 2003 *Parent Partners: Creative Forces...* discussing the inclusion of family members in health care settings to determine what is working well in the clinics and what may need to be

done to promote the “Family Partner” role in clinics and organization efforts (Family Partners Annual Report 2004/2005). Contact: jan-moss@ouhsc.edu.

### **Interdisciplinary Partnership Course**

- The Human Experience of DisABILITY is an interdisciplinary partnership of Oklahoma University College of Nursing and Oklahoma LEND. This program extends The Human Experience of DisABILITY, a 2-hour course, across disciplines at the University of Oklahoma Health Sciences Center and via the Internet to the nationwide LEND network. The course is presented from the perspective of people with disabilities and their families, stressing abilities rather than medical diagnoses and disabilities. Contact: Janet-wilson@ouhsc.edu.

### **AND BEYOND...**

FM provides an opportunity for trainees to develop skills through partnering with families that cannot easily be obtained in the classroom or clinic. These partnership skills are part of the leadership skill set that is a core element of the LEND training program. Partnering with families is one of many ways trainees can experience these skills. The listing below offers additional opportunities for trainees to build upon the skills learned through FM and explore partnerships with local, state, regional, and national systems working with families of people with disabilities.

### **Additional partnership opportunities for trainees might include mentoring with:**

#### **Federal, State, and Local Entities:**

- Other LEND programs
- UCEDDs
- Title V Programs
- Local and State MCH grantees
- Local hospitals
- Community leaders
- Local Interagency Coordinating Councils
- Early Intervention Program (IFSP process), Public School Special Education Office (IEP process)
- Divisions of Special Education
- Developmental Disabilities Councils
- Protection and Advocacy Organizations
- Parent Training Information Center (PTIs)
- Mayors’ Offices on Disability
- University Offices on Disability
- State Departments of Mental Retardation, Mental Health, Developmental Disability Services, or Rehabilitation Services
- Traumatic Brain Injury Service Coordination Programs
- Medical Home Projects
- EPSDT/CHIP programs (Early and Periodic Screening, Detection and Intervention / Children’s Health Insurance Programs)
- State Medicaid Advisory Commissions

### Advocacy Groups or Disability-Specific Organizations:

There are a multitude of projects in which trainees might become involved to gain experience with local, state, regional, or national groups such as those previously listed.

- AAMR (American Association on Mental Retardation; in 2007 the name changes to AAIDD: American Association on Intellectual and Developmental Disabilities)
- ADAPT
- Autism Society of America
- Brain Injury Association of America
- Centers for Independent Living
- Centers for Non-Profit Management
- Consumer Advisory Boards
- Family Voices
- LDA (Learning Disabilities Association of America)
- Local/State Parent Organizations
- NADD (National Association for the Dually Diagnosed)
- NAMI (National Alliance for the Mentally Ill)
- National Federation for the Blind
- NDSS (National Down Syndrome Society) or NDSC (National Down Syndrome Congress)
- NORD (National Organization for Rare Disorders)
- Parent Training and Information Centers
- People First
- TASH
- The Arc
- United Cerebral Palsy
- Voices for America's Children

### Projects

- Participate in Partners in Policymaking
- Complete a public policy project
- Participate in a Youth Leadership Forum
- Develop or facilitate a support group
- Participate in Sibshops, the Sibling Support Project, or other programs for siblings of individuals with disabilities
- Conduct a collaborative needs assessment with agencies or consumer groups
- Participate on the advisory council for Special Olympics
- Become involved in the court system for children at risk
- Develop a budget with agencies or consumer groups
- Develop legislation
- Participate in person-centered or family-centered planning
- Write or review a grant
- Participate in information dissemination activities

### AND BEYOND...





# SUMMARY

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*The family mentorship was an invaluable component of the LEND training program. Nowhere in the academic, classroom or lecture series did I feel as challenged and rewarded as I did in the family mentorship experience. It truly transitioned the textbook teachings into a human experience.*

*~A former trainee*

Family Mentorship is an effective training component for many LEND programs. We hope this guidebook helps readers appreciate the extent to which an FM experience benefits trainees and faculty as well as many families of individuals with disabilities.

The effects of the FM program extend far beyond its own time span. Past LEND trainees frequently describe its positive impact on their training. They often point to the Family Mentorship experience when asked how their training affected their future professional lives. Developing a personal rather than professional relationship with the family of a person with a disability can give trainees a deeper appreciation of families and increases their capacity to have a family-centered approach. Family Mentorship provides trainees the opportunities to acquire the knowledge, values, and experience they need to be better equipped to ensure that the delivery of care and resources occurs in a culturally sensitive and practical way.

Similarly, mentoring families appreciate the opportunity to play an active role in the education of health care professionals who will one day provide care for children like their own. Families have the unique ability to provide information about the qualities they look for in health care professionals. By sharing their daily challenges, joys and priorities, families teach future professionals to look beyond an individual's disability or diagnosis and to recognize and respect the knowledge and importance of the family's role.

## APPLICABILITY TO NON-LEND TRAINING PROGRAMS

Family Mentorship is an excellent model for involving families in the training of health, allied health, and special education professionals across the LEND network. It is increasingly being introduced in similar training programs. Many families feel that they would have received better services for their family member with a disability had their doctor or other health professional received the kind of people-to-people sharing of life experiences that mentoring families provide. The authors hope that this guidebook will encourage the FM model in the training or continuing education of interdisciplinary or discipline-specific professionals.

## USING THE APPENDICES

FM Coordinators and others beginning or enhancing an FM are encouraged to move beyond the body of this guidebook and take advantage of the information contained in the Appendices, located in the LEND section of [www.aucd.org](http://www.aucd.org):

- Appendix A contains documents referenced in this guidebook, including a variety of FM documents in use by individual LEND programs.
- Appendix B contains a variety of additional reference documents used in LEND FMs.
- Appendix C lists a sampling of FM programs that exist in some non-LEND training programs across the country.

- Appendix D contains a link to the LEND network directory and a listing of FM Coordinators at LEND programs across the country who have volunteered to give technical assistance to anyone wishing to begin or enhance their FM program. These individuals and other involved faculty at any LEND can be a great resource when looking for new ideas and resources. They are ready and willing to share their experiences with and enthusiasm about Family Mentorship.

## IN CONCLUSION

The LEND Family faculty who compiled the Guidebook hope that it is useful to trainees, faculty, family members, and others interested in beginning or enhancing an FM experience in professional training programs. We hope that the Family Mentorship model becomes more widely used in the training and continuing education of human service professionals and practitioners who work with people with disabilities.



***I view** my LEND training as one of the most valuable pieces of my educational experience. Within the context of LEND I found the family mentorship and family presentations in the classroom setting to be the experiences I will always remember and relate to. I always remember issues and ideas when I can put faces to them. The family interaction brings reality to the academic ideals. One cannot underestimate the value of a family being able to tell their story and share their life with a student who wants to pursue work with children with special needs. Those families had a profound impact on me and how I do my work.*

*~A former trainee*

## COMMENTS

We welcome and encourage feedback on this guidebook: to post your thoughts, comments, and questions about the Guidebook, visit the AUCD LEND Family Faculty Message Board within the LEND section of [www.aucd.org](http://www.aucd.org).



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For more information on LEND Programs, Family Mentorship, or for additional copies of Promising Practicess in Family Mentorship: A Guidebook for MCHB-LEND Programs, contact AUCD at 301-588-8252 or [www.aucd.org](http://www.aucd.org).

