

Overall, this was an amazing experience that changed the way I think about disability as a professional, inspired me to become more involved in policy and advocacy work, and gave me a deeper understanding of what it means to have a child with a disability.
— 2017 LEND trainee



We love being a Mentor Family because it gives us a chance to help future professionals become the type of providers we want our daughter to have access to. We want them to understand what it's like to raise a child with a disability, how our families are similar and different from typically developing families, what supports and services we most need, how systems do and don't work for us, and what we would like to see be different. We also tell them this is their chance to ask questions that might not be appropriate in a professional setting but that they really want answers to. We believe that our trainees will be better practitioners and policy makers because they have spent time truly getting to know a family with a child with a disability.
— 2017 Mentor Family

Background and Significance

Caring for a child with a disability is a complex task. Understanding families' needs and experiences is necessary for the MCH workforce to improve systems of care for children with disabilities. Families can play a critical role in shaping MCH trainees' understanding of what they need to live happy and healthy lives.

The Wisconsin Leadership Education in Neurodevelopmental and Related Disabilities (WI LEND) program at the Waisman Center, UW-Madison, provides a Family Mentor Experience (FME) that teaches trainees about families' real-life experiences. The FME impacts more than a dozen teaching families and over 30 trainees from 16 disciplines each year.

Purpose

Through joining families in everyday activities, trainees broaden their understanding of experiences and perspectives of children with disabilities and their families. The FME also benefits mentor families and the WI LEND program.

Trainees:

- Gain insight into families' daily lives
- Observe how families navigate healthcare and community services
- Learn what family-centeredness really means to families
- Ask questions in a safe environment
- Refine communication, negotiation, and interdisciplinary skills
- Gain insight into how their profession fits into the broader context of the life of a child with a disability

Families:

- Share their expertise on parenting a child with a disability
- Develop leadership, advocacy, and teaching skills

WI LEND:

- Cultivates a cohort of mentor families

Family Mentor Coordinator Role

- Recruit and screen families
- Introduce Family Mentor Experience to Trainees
- Match pairs of trainees to families
- Coordinates Get Together
- Guide families and trouble shoots issues
- Mentor trainees, trouble shoot issues, and process trainees' experience
- Summarize trainee key learning and share with families

Family Mentor Experience → 4 visits over 4 months

- **In-home visit** to learn about daily life
- **Two community visits** (therapy, school visit, sporting event, doctor's appointment, restaurant, etc.) to gain insight into family's experiences in out-of-home settings
- **Final visit** to bring closure and thank mentor family by sharing what learned and appreciation for family's time, mentoring, and experiences

Encouraging Self-Reflection and Integration with Program's Core Content

- Self-reflection after each visit
- Wrap-up activities (large and small group processing)
- Meeting with the Family Mentor coordinator
- Identify and share with FME Coordinator what most appreciated/found beneficial/learned

Self-Reflection Topics

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| <ul style="list-style-type: none"> • Because of what experienced, what would now tell someone coming into discipline • Experience's impact on trainee • What surprised trainee* • Similarities and differences noticed between families with and without a child with a disability • How experience changed view of discipline* • How experience fits with trainee's LEND goals | <ul style="list-style-type: none"> • How experience informs or shapes post-LEND leadership goals • Policy issues affect on Mentor Family* • Impact of understanding of Interdisciplinary and Family-Centered practice* • Relevance of Research, Evaluation, and Dissemination on Mentor Family and how to best share results • What now want to learn more about* |
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* Topic also included in Small Group Wrap-Up

Large Group Wrap-Up Topics

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| <ul style="list-style-type: none"> • Comments or questions about what groups shared • How well what has been shared reflects all trainees' experiences | <ul style="list-style-type: none"> • Anything to add • Similarities or different between partner's observations/experiences/learning and why think that is |
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Family Mentor Activities Timeline

Recruit and Screen Mentor Families	Collect and Update Mentor Family Bios	Introduce Family Mentor Experience to Trainees	Trainee Pairs Rank Mentor Families and Identify FME Goals	Opportunity for Trainee Pair and Mentor Family to Meet at Get Together	Readings (Optional)	4 visits in 4 months	Meet with Family Mentor Coordinator	Wrap-Up in Seminar	Key Learning to FM Coordinator; Trainees Thank Mentor Family	Thank You and Summary of Key Learning to Mentor Families
Before Training Year Begins	Week 1	Week 3	Week 4	Weeks 5-17	Between Weeks 5-17	Week 18	Shortly After Week 18			