

LEND Family Mentorship Models



Forward

Every Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program is unique and offers different academic, clinical, leadership, and community opportunities. This also includes different approaches to family-professional partnerships and training on family-centered care. Family mentorship of future providers, where families share their lived experience with trainees from professional disciplines, is one approach that several LEND programs across the network have implemented. While not required, many find that family mentorship of professional trainees is an excellent model to promote effective, caring family-professional collaboration and has long-term benefits for the workforce serving individuals with developmental disabilities and autism. *A mentor provides guidance to help grow knowledge and experiences to help the mentee grow into the best version of themselves; in LEND, that mentor is a leader in the disability community who has lived experience.* This training strategy gives trainees a look into a “day in the life” of families that cannot be taught in classrooms or found in books. Family mentorship also benefits families themselves. Families learn to mentor, which increases their self-esteem and helps them realize that their lives and stories matter; this may lead them to be active advocates for their children and their community. This document is written by a group of LEND programs for other LEND programs and contains several examples of this experience from across the network.



Table of Contents

3	Alabama LEND
6	CA-LEND
8	Iowa LEND
10	Kansas LEND
12	Miami LEND
14	NY - CERC LEND
16	Oklahoma LEND
20	Oregon LEND
23	Pittsburgh LEND
25	Rhode Island LEND
26	South Dakota LEND
28	Utah LEND
30	Virginia LEND
32	Washington LEND
34	WIHD LEND
36	Wisconsin LEND



UAB LEND - Day In The Life

The University of Alabama at Birmingham (UAB) LEND program that highlights the family perspective is referred to as the Day in the Life Program (DIL). The goal of this program is for trainees to learn from a family or self-advocate about the impact of the lived experience, which would include daily activities, their experience of working with professionals from various disciplines and the responsiveness of service systems to the family's needs and desires.

Through this experience, our hope is for trainees to:

- learn to recognize that services or recommendations that may appear to be critically important from a professional perspective may decrease in importance when viewed within the context of the family's daily routine,
- learn about the challenges families face when advocating for a child,
- deepen their appreciation of these families, and
- increase capacity to work in a family-centered manner.

Who

The goal is to identify places where the trainees can meet, observe, and can develop a relationship with family members or Self-Advocates which may result in a home or community visit. Sources for identifying families or Self-Advocates include:

- contacting a family resource center, support group or disability specific organization such as Centers for Independent Living (CIL) or your state DD Council local chapters of TASH, People First, etc.,
- Title V state agencies local partnering agencies that provides services for people with disabilities throughout the lifespan ([Horizon's](#), [Mitchell's Place](#), [Triumph](#), [Full Life Ahead](#)), and
- a mentor family can be assigned for trainees. All families, whether chosen or assigned, need to have prior approval from the faculty mentor.

When

Each trainee at the UAB LEND will develop an Individualized Training Plan (ITP) that will include an 8-hour time commitment for the DIL activity. This can be completed during their training period, which may range from a few months to two years.

The family perspective is displayed throughout the UAB LEND and is demonstrated first at orientation, reinforced during participation in the DIL activity and strengthened with other involvement during the year.

Orientation at the UAB LEND begins with a viewing of the short film [Intelligent Lives](#), followed by a debriefing. This activity highlights the importance of the family voice that we want to emphasize during their training.



During the fall, we offer the livestream of a portion of the Texas Children's Hospital's Annual Chronic Illness and Disability Conference as another opportunity for the trainees to be engaged with needs for the disability community.

The UAB LEND structure is for didactic classes (Core lectures) throughout the calendar year each Thursday from 12-1:30pm that all trainees are expected to attend. The lectures range from discipline specific to partner programs to the family perspective. Each year, there are approximately 5-7 lectures designated to the family voice. The topics vary from advocacy activities to personal stories delivered by Self-Advocates and parents. Two of these are designated for trainees to present and discuss their experiences with Day in the Life (DIL).

What

Trainees complete a pre and post-test for evaluation of the family perspective. As they take the pre-test, it shows them what to consider as they look at the family perspective. The post-test allows them to see their growth in viewing the family perspective during the year. We encourage trainees to participate in DIL as pairs, since they travel to off-site locations during visits.

After the visit, trainees write a reflective summary of the DIL experience incorporating some information about the family but concentrating on what they have observed. We remind the trainees that even though they have professional knowledge and experience, we have asked families to participate in their training; the families have not asked to be evaluated.

Many of the trainees present a Core Lecture presentation, where they prepare a short (10-15 minute) PowerPoint about their experience. Outline for the presentation includes:

- Overview of the family from the home and community visit,
- Trainee's understanding of the child's disability,
- How it may affect their daily life as well as their families,
- Recommendations the trainee see that the family or child would benefit from,
- Any concerns or feelings the trainees have about the visit,
- Strengths observed in the family,
- Summary and reflection of the experience and how this experience will impact how the trainee will work with families in the future.

Where

Activities can be in-person or virtual. The key is for trainees to find a way to engage outside of the typical clinic space. When trainees go on a home visit; we ask that they go in pairs. We encourage participation in whatever activity or event that the family or Self-Advocate wants to share.



How

Guidelines for an in-person visit include:

- After selecting the family, trainees begin with an informal discussion to get an overview of the family's story, gathering information on the types of services that the child/family currently receives and what the family experiences on a regular basis.
- Trainees should include one observation in the home and one community-based experience (e.g., attending an IEP meeting, going to the market, library, sports game).
- This assignment can be accomplished in one day or through separate observations. Be aware of the family's strengths but also pay particular attention to their challenges. *Ask the family what they think professionals need to know about working with families of children with disabilities.*

Example of a virtual visit:

Join advocates from [People First of Alabama](#) (PF) with updating their Transition Booklet.

Project

Each trainee will be paired with a young adult advocate and given a section of the Transition Booklet to update. Updating the booklet will be comprised of:

- verifying correct link connections,
- organizing an internet search for additional information for designated section area,
- correcting and updating of designated section narrative, as necessary.

This activity will allow the trainee to spend valuable time with a person with a disability and accomplish the goals of DIL. The PF self-advocate will primarily be involved with providing the lived experience knowledge to include in the handbook, which cannot be found searching the internet. The trainee will be responsible for taking the lead on the project, coordinating activities, and mentoring the advocate as appropriate.

Additional Information

Trainees will identify a family of a child with special needs as an additional activity to contribute to family-centered professionals.

UAB LEND contact information:

Linda Russo, Family Discipline Coordinator

Email: lvrusso@uab.edu

Website: <https://www.uab.edu/civitansparks/training-training/lend>



CA-LEND's Day in the Life Experience

The Day in the Life Experience is an opportunity for trainees to learn from families by being with them. They meet outside the clinical setting and see what families experience on a regular basis; see the events that make up a family's life. By attending everyday activities such as doctor's appointments, trying to get the family off to school, or going to a restaurant, they have an opportunity to see firsthand the challenges that families face daily. The goal is to deepen their appreciation of families and increase their capacity to work in a family-centered manner.

Of course, with the program being remote this year, it was not realistic (or safe) to have our fellows go into people's homes. Instead, we had small group in-depth discussions with the Self-Advocates and family members who present at our monthly first-person perspective presentations.

Who

- LEND First Person Perspective Presenters
- LEND Module Coordinators
- LEND Family Support Discipline Director

When

Pandemic update: Fellows participate in an hour small group discussion with the First-Person Perspective presenter for that month's module.

What

Our remote format consists of a small group (4-6 fellows) in-depth discussions with the Self-Advocates and family members who present at our monthly first-person perspective presentations, with the purpose of having a deeper understanding of the individual or family experience. Each fellow participates in one group session of 4-6 fellows. Prior to the session, they write down what they anticipate they will learn and prepare a couple of questions. After the session, they record what they have learned and how it will impact their practice moving forward.



Where

On Zoom during the LEND Day

How

Please refer to “What” and “Where” sections

Additional Information

In the past, fellows were required to identify their own families. The reason for this is two-fold.

- 1) We wanted a more organic experience with families who had no prior experience at mentoring fellows.
- 2) We wanted the fellows to fully understand that disability exists in the community, and they didn't need someone to find families since families are all around them. Our only requirement was that it could not be a family with which they had a personal (friend or relative) or professional (patient or client) relationship. Many fellows would trade families with each other so that they met that requirement.

CA-LEND contact information:

LaTysa Flowers, Family Support Director

Email: lflowers.ca.lend@gmail.com

Website: <https://www.uscucedd.org/what-we-do/training-programs/ca-lend>



CALIFORNIA LEADERSHIP
EDUCATION IN
NEURODEVELOPMENTAL
DISABILITIES



USC University of
Southern California



Iowa LEND Parents as Mentors (PAM)

The Iowa LEND Parents as Mentors (PAM) program provides trainees the opportunity to learn about families who have a child with a disability from the True Experts-the parents. The PAM program was completely virtual during COVID and since has offered a hybrid model. During the first semester in PAM, our trainees have a total of three visits (via in-person, Zoom, Facebook Messenger) with their assigned families.

Who

Each year we recruit between seven to nine families with children representing varying disabilities, including one mentor family in Puerto Rico.

When

In mid-September, the PAM Coordinator facilitates orientation for the mentor families and trainees. This is offered during the evening to accommodate both groups' busy schedules and serves to highlight the purpose of the PAM program, visits, and desired outcomes. After the presentation, the audience breaks into groups (either in person or via zoom breakout rooms) where the families and trainees get a chance to meet each other and set up their first visit. Each family is assigned a "team" of 3-4 trainees that embodies a variety of disciplines.

What

Below is a list of objectives:

Objective 1: Demonstrate knowledge of and skill in practicing patient-family centered care in clinical and community settings

Objective 2: Demonstrate cultural competence through effective communication and interaction with people regardless of differences

Objective 3: Demonstrate effective family and professional partnerships through respectful involvement of people with disabilities and their families in all aspects of care, planning, and shared decision making.

Objective 4: As an MCH leader, continually analyze and self-reflect on the impact of your values, beliefs, communication styles, cultural influences, and experiences (implicit biases).

Objective 5: Identify underrepresented populations, health disparities and strategies to address them at a systems level.



Where/How

Due to COVID restrictions for in-person visits last year, we purchased a small camera similar to a GoPro, for each family to use to make three videos in an effort for the trainees to get a “behind the scenes” look of “a day in the life” of their PAM family. The families were given guidance on the content desired for each video. With the written consent of the families, we were able to archive the videos to use again this year and going forward. In 2022 the trainees watched the first video of their assigned family and took notes of what they learned and any questions they may have. After this step was complete, the trainees had their first visit with the family (either in person or via zoom) to meet and get to know the child as well as any siblings and extended family and have some fun. After the first visit, each of the trainees submitted a reflection paper and was given feedback by the PAM Coordinator. After the second and third visits each team had a zoom meeting with the Parents as Mentors Coordinator to describe what they learned. The last assignment for the trainees in the 1st semester is to write a final reflection paper which the PAM Coordinator provides written feedback and sends the final reflection paper to each trainee’s Core Faculty Director. This reflection is also shared with their assigned PAM family at the end of the year. After all visits and assignments are complete, the PAM Coordinator facilitates 2 Roundtable Discussions which are held during the weekly Tuesday and Thursday seminars. This allows each of the teams the opportunity to share, one at a time, the valuable lessons they learned from their PAM families and how they plan to use this experience in their future lives and careers.

Iowa LEND Parents as Mentors (PAM) contract information:

Jackie Nau, Parents as Mentors (PAM) Coordinator

Email: jackie-nau@uiowa.edu

Website: <https://uihc.org/ucedd/iowa-lead>



**Iowa Leadership Education in
Neurodevelopmental and Related
Disabilities
(LEND) Program**



Kansas LEND

The Kansas LEND experience provides trainees an opportunity to gain insight and perspective into the lives of families who have a child with a disability. The objective is for trainees to remember this experience when they move into their professional careers supporting individuals and families in the disability community.

Who

- Families within Kansas
- Due to our program being virtual, we will look to rural and frontier areas
- Long-term and Medium-term trainees



When

The required time is over the course of an academic year, 1 hour a month from September to March (off for December). Trainees and families schedule their meetings. It is fine if they choose to meet additionally.

What

- The experience gives trainees a virtual glimpse into a family's daily life; times may differ throughout the day.
- Trainees will consider the family they are paired with throughout the year as they discuss different topics in class and other training opportunities.
- Each year community partners present their supports and services for families during a Community Connections training for trainees. Trainees are to consider which ones assist their family directly and discuss at a future meeting.
- Assignments throughout the experience include developing an infographic spotlighting a resource; creating a short video explaining specific support to be posted on social media; writing a reflection paper; and reflecting on a current piece of legislation that will help the family they are paired with during the program.
- [Sample syllabus information](#) and [sample family mentorship experience organization/question guide for trainees](#)



Where

- Virtual in-home
- Beyond the virtual in-home experience, if a family should invite the trainee to a virtual IEP, therapy (such as horse riding or dance lessons), or a doctor appointment, they are encouraged to attend. This helps trainees gain insight into what the family experiences in these appointments.

How

- Families are recruited from past immersion experiences and our Kansas LEND Family Education Series listserv.
- Trainees are encouraged to choose a family who has a disability they are not familiar with for their mentorship.
- Currently, visits are done via Zoom, though they may participate in a community outing in a local and safe place.
- Virtual also allows families in the more rural areas of Kansas to participate, which highlights the lack of services, supports, and resources in those areas.
- Families will receive \$50 for each of the six, 1-hour meetings for a total of \$300.00.

Trainees are provided with a list of guiding questions (examples: September Getting to Know You, October Learning about Supports and Therapies, November school supports upcoming holidays) should they need for each month they meet. They are not expected to stick to the guide; they should let the conversation flow naturally.

Kansas LEND contact information:

Stephanie Coleman, Family Discipline Supervisor

Email: scoleman3@kumc.edu

Website: [https://www.kumc.edu/school-of-medicine/academics/departments/pediatrics/academics/leadership-education-in-neurodevelopment-and-related-disabilities-\(lend\).html](https://www.kumc.edu/school-of-medicine/academics/departments/pediatrics/academics/leadership-education-in-neurodevelopment-and-related-disabilities-(lend).html)



University of Miami's Understanding the Family Professional Partnership (UFPP)

The University of Miami's Understanding the Family Professional Partnership (UFPP) series at the Mailman Center for Child Development allows trainees to learn about the concerns and experiences of families who have a child(ren) with autism spectrum disorder (ASD), intellectual and developmental disabilities (ID/DD) and chronic health care conditions.

Who

The lecture series is delivered primarily by parents of children with disabilities, adults with disabilities, and clinicians who work with individuals with intellectual and developmental disabilities or chronic health care needs.

When

The program occurs year-round on Fridays from 1:00 pm-3:30 pm for a 4-week rotation. LEND trainees are scheduled a specific 4-week rotation based on their schedule and trainee status (short, intermediate, or long-term).

What

Understanding the Family-Professional Partnership (UFPP) is an interactive, interdisciplinary discussion series. Small groups of graduate students in the following disciplines attend these discussions: social work, speech pathology, audiology, pediatrics, physical therapy, psychology, public health, occupational therapy, self-advocate, family leader, and education interns. [UFPP's Syllabus](#)

Where

Currently, the sessions are held via Zoom for now due to the pandemic situation.

How

Family consultants are hired to teach three sessions of our UFPP curriculum:

- Receiving Diagnostic News, Family-Centered Care, and Transition.
- Family consultants receive \$75/hr. for their time.



Additional information

The objectives of the *Understanding the Family Professional Partnership* program are:

- To gain the basic knowledge, skills, and attitude necessary to effect systems-wide change to improve the quality of life for Children with Special Health Care Needs (CSHCN) and their families.
- Increase awareness of and how cultural reciprocity factors influence providers when delivering diagnostic news.
- Identify disciplines that comprise an interdisciplinary team and explain their role on the team.
- Recognize services and supports needed by families who have children with disabilities.
- Understand the concept of Family and Professional Collaborations, the medical home model, and best practice communication skills.
- Learn about assistive technology and the FFAST program in efforts to aid their families.
- Appreciate the perspective of adults with disabilities and lessons learned for a more disability-sensitive practice.

University of Miami's Understanding the Family Professional Partnership (UFPP) contact information:

Cristina L. Pujol, M.S., CCC-SLP, LEND Training Director

Email: cxl885@med.miami.edu

Website: <https://med.miami.edu/centers,-a-,institutes/mailman-center/education/leadership-training-opportunities/lend>



MILLER SCHOOL
of MEDICINE



ROSE F. KENNEDY CENTER - CERC LEND

The Rose F. Kennedy Center - CERC LEND experience provides trainees an opportunity to gain insight and perspective into the lives of families who have children and youth with intellectual and developmental disabilities (ID/DD). The objective is for trainees to remember this experience when they move into their professional careers supporting individuals and families in the disability community.

Who

We have a group of four parents who are all moms with children with intellectual disabilities, developmental disabilities, or special health care needs receiving evaluations and/or services at CERC. Due to the COVID-19 pandemic, the program is virtual. The parents learned how to use the internet, work online via Zoom, and navigate daily to be integrated into social networks to collect and keep up to date with current resources.

When

- The required time of the program is over an academic year, starting at the beginning of September and graduating at the end of June. We offered training in the form of lectures and small virtual group discussions weekly and monthly. There may also be opportunities to attend conferences outside our center, with support and all expenses paid.
- In our program, we are flexible to adapt to the needs of our family trainees and the obligations that come from having to take care of children with special needs daily.

What

- The experience of being part of LEND Family Discipline Program gives trainees a virtual lens into a family's daily life.
- Family Trainees will learn to develop advocacy skills throughout the year by discussing various topics in class, working on some assignments, and attending the weekly Core Seminars.
- Trainees have worked on different assignments, gained confidence in being an effective partners, and demonstrated leadership on the interdisciplinary team.
- The assignments throughout the experience include developing a PowerPoint presentation based on their personal experience when they received the diagnosis of their child(ren) with disabilities or special needs. All Family Trainees presented this PowerPoint through Zoom to other students and medical staff attending the Core Lecture, answering questions related to the topic at the end.



Where

- Family Trainees are attending the year 2020/2021 program virtual – in-home.
- Beyond the virtual in-home experience, if Family Trainees are invited to attend a virtual event outside our center, they will have all fees paid.

How

- Families are recruited from those who showed particular interest in being part of the program and the availability of time to commit to the required task.
- Family Trainees are encouraged to share with fellow Lend Trainees their point of view of being parents of a child(ren) with disabilities or special needs. Everyone can learn the invaluable work on advocacy, daily systematic work, and perseverance that this implies.
- Currently, meetings are done via Zoom, though they may participate in a community outing in a local and safe location.
- Virtual also allows families to participate in receiving support and resources in different areas, i.e., understanding the history of the disability, practice, advocacy at the individual, parent, group, and systems levels, demonstrating an understanding of developmental disabilities and related issues as they pertain to a variety of families.

Additional information

Trainees complete the same Self-Assessment at the beginning and end of the program year to see what they have learned and the areas in which they have worked.

Rose F. Kennedy Center - CERC LEND contact information:

Marcelle Pachter, LEND Family Faculty Coordinator

Email: Marcelle.pachter@einsteinmed.edu

Website: <https://einsteinmed.edu/centers/childrens-evaluation-rehabilitation/training/lend.aspx>



The Rose F. Kennedy
Children's Evaluation &
Rehabilitation Center



Oklahoma Family Mentorship Program

Family members play a vital role in improving the services and supports for people with intellectual and developmental disabilities and are key in educating decision-makers about strategies to make programs and policies more effective and responsive for meeting needs. Effective collaboration between family members and professionals is essential to the OKLEND Core Principles of Family-Centered/Person-Centered Services, Interdisciplinary Teaming, Cultural Competency, and Inclusive Community-Based Practice. To achieve real collaboration, all participants must be equal and respected members of the team. True Family-Centered services require that families be not only allowed at the table but are viewed and valued as equal partners.

Approaching the family professional partnership during the learning phase for health care professionals is an effort that takes family and patient centered care to a new level. Facilitating this learning from families who have experienced health care delivery from their own personal journey, has proven to have a long-term impact to all learners after graduating. This is not only true from the lived experience but also partnering with families who serve at a high regional or state level for improving systems by family advocacy at all levels.

Who

- Oklahoma Family Mentors are a group of diverse family leaders bringing multiple perspectives to the learning opportunity.
- Family Mentors for the Family Life Experience opportunity are family members who have one, two or three children that have experienced an intellectual disability, developmental disability and/or chronic health conditions as well. Additionally, one set of Family Mentors for the Family Life Experience includes a mother-daughter team.
- Family Mentors for the Family Advocacy Experience include family members who are directors of not-for-profit agencies supporting people with different disabilities such as autism spectrum disorder, Down syndrome, rural life, family to family networking and support, mental and behavioral health, faith and urban development, Hispanic and Black/African American community support.

When

- The Family Mentoring Experiences are required practicums for all OKLEND long-term trainees.
- Family Mentoring for the Family Life Experience is offered in the first semester. All experiences must be completed before the second semester Family Mentoring.



- Family Mentoring in Family Advocacy is offered in the second semester.
- All practicums, Family Mentoring experiences must be completed before the end of April of the given year.

What

The Oklahoma Family Mentorship program offers the opportunity for all students to learn from families.

Family Mentorship in the Family Life Experience:

- Objectives
 - During the Family Life Experience Family Mentor Practicum, the OKLEND Leadership Interns will:
 - Visit with a family of a child or adult child with developmental disabilities.
 - Have a glimpse into something about the day-to-day activities of the family's life.
 - Have a conversation with the family member and possibly their child with disabilities or self-advocate to learn more about their unique situation.
- Outcomes
 - After completing the Family Life Experience, Family Mentor Practicum, the OKLEND Leadership Interns will:
 - Recognize and describe challenges surrounding families of children (adult or youth) with disabilities.
 - Identify some of the unique and creative strategies families use to help them throughout the day.
 - Interpret how the challenges or obstacles families face when interacting with the community, whether it is for a medical appointment, shopping, entertainment or to participate in a faith centered activity, impact their daily lives.

Family Mentorship in Family Advocacy Experience:

- Objectives
 - During the Family Advocacy Mentor Practicum, the OKLEND Leadership Interns will:
 - Visit with a family of a child or adult child with developmental disabilities.
 - Hear how family advocates are trained or supported to be system's advocates.
 - Learn from the Mentor about opportunities for professionals to affect positive change for children with disabilities or special healthcare needs.



- Outcomes
 - After completing the Family Life Experience, Family Mentor Practicum, the OKLEND Leadership Interns will:
 - Identify ways family members are using their lived experience in creating systems change
 - Identify at least one unique or creative strategy family mentors have used to improve services for children with disabilities
 - Explain how a parent professional partnership positively impacted a support, service, or system for a child with disabilities in Oklahoma

Where

Family Mentoring is offered wherever family members live or have opportunities to advocate.

Family Life Experience:

Prior to the current pandemic the Family Mentoring in Family Life Experience has happened, at car shows, family barbeques in the back yard, church activities, dental and medical appointments, school, and IEP meetings, visiting in mother and then daughter's home and many other typical family life locations. During the pandemic, Family Mentors have moved to virtual visits. Each visit offers the opportunity to meet most family members and then usually a one-on-one conversation with the Family Mentor is offered.

Family Mentoring Experience:

Prior to the current pandemic the Family Mentoring in Family Advocacy happened at state level advisory, board, and commission meetings along with non-profit board meetings or planning meetings. There have been times when this experience is held at the state Capitol for a legislative advocacy or education opportunity has arisen. It should be noted that for the Family Advocacy Mentoring experience there is a pre- and post-meeting requirements for the Family Mentor and the trainee. The purpose of pre-meeting requirement is so the trainee has a good understanding of the purpose of the meeting, the design and requirement of the committee. The post meeting requirement gives the trainee the opportunity to debrief and reflect. During the pandemic, most of the above-mentioned opportunities happened but were moved a virtual meeting format.

How

The Oklahoma Family Mentorship Program is a project out of the Center for Learning and Leadership/UCEDD. The family faculty for the OKLEND program is also the UCEDD director of the Family Mentorship program.

Payment is made to all Family Mentors for their time and expertise. Supporting and training is offered by the UCEDD/OKLEND staff/faculty. Recruitment is typically from OKLEND graduates, the Oklahoma Family Leadership Network and other leadership opportunities including Partners in Policymaking.



Each Family Mentoring experience, Family Life and Family Advocacy, the trainees will review the Guide and choose the Family Mentor that offers them the greatest opportunity for their personal and or professional interest. The choices must be as equal as possible which means some trainees will need to choose their second option to keep the Family Mentoring balanced.

Each year a Family Mentorship Guide for each experience is created for the OKLEND trainees. The Guide offers individual information about each Family Mentor, their family life experience, their focus, and perspective and for the Family Advocacy experience, a short video introduction about their family is included.

Additional Information

Oklahoma Family Mentorship program currently has 14 Family Mentors in the program.

Sample Guides: [Family Life Experience](#) and Family [Advocacy Experience](#)

OK LEND contact information:

Wanda P. Felty, OKLEND Core Faculty Parent-Family

Email: wanda-felty@ouhsc.edu

Website: <https://ouhsc.edu/thecenter/Projects/Training-and-Collaboration/OKLEND>



Oklahoma Family Mentorship Program



LEND

at

Child Study Center

*Developing leaders across fields of service to work
with people with disabilities and families*



Oregon LEND Program

The LEND Family Mentor program allows health care trainees to learn directly from families about life with a child who experiences a disability. By the end of their fellowship, trainees have learned:

- All families and children have strengths. A family is the sum of all its members, including the extended family.
- Families are diverse.
- Family-to-family communication and support are essential.
- Children and youth with disabilities and their families live most of their lives on their turf in their home and community, outside clinical settings.
- Family participation better prepares trainees to work with families post-LEND.
- The basic principles of positive family-professional collaboration.

Who

- Family Faculty: responsible for recruiting, selecting, and orienting mentors.
- Family-Professional committee: (two professionals/two families, including one former trainee). The committee meets twice yearly for problem-solving, ideas, and support as needed.
- Mentors: 13-15 diverse parents within a 30-mile radius of the OHSU campus. Most have been Mentors for 3-5 years. Depending on circumstances, mentors “age out” when their child reaches 19–22.

When

- Late spring: recruit and select new mentors (if needed),
- Late summer: one all-mentor meeting to review guidelines and answer questions.
- September: matching process between trainees and mentors.
- October: mentors submit payment information, and the stipends are processed.
- October- December: visit one in the home; trainees enter a brief journal entry for documentation.
- January – March: visit two in a medical or educational meeting, and trainees submit a journal entry.
- April – June 15: visit three in a community setting; trainees submit a journal entry.
- Summer: Family Faculty works on quality improvement for forms, processes, etc., if needed.



What

Mentors are assigned a trainee to work with from September through June. They meet three times with the trainee, once per quarter, in three different settings:

- The family home for a “get acquainted visit.”
- A medical, dental, or therapy appointment or an Individualized Family Service Plan (IFSP)/Individualized Education Plan (IEP) meeting.
- An outing to something the family typically attends, such as a park, grocery store, etc.

Family mentors agree to:

- Be themselves and host the trainee in a spirit of openness and warmth. Include siblings and spouses in the meetings whenever possible.
- Speak frankly, be willing to answer questions, and note both the strengths and challenges of the family experience.
- To honor to the best of their ability, appointments with trainees.

Where

One meeting is in the home, one at a medical or educational appointment, and one in a typical community setting. During the pandemic, when no in-person visits are allowed, mentors/mentees made virtual visits to the best of their abilities, incorporating a telehealth visit if possible.

How

- Family mentors fill out an application, then interviewed by the Family Faculty. No references are required at this time, but we are considering them.
- Mentors receive \$250 in the late fall as a thank you for their three visits with mentors.
- Family Mentors agree to honor, to the best of their ability, appointments with trainees and call the trainee as early as possible if something comes up. They are encouraged to take the lead in recommending days/times for the meetings. They are encouraged to “host” the trainee in their home and offer a meal or a place convenient to both but are not permitted to serve alcohol to trainees.
- Mentors are invited and encouraged to attend their trainee’s research presentation and trainee appreciation/graduation.
- Mentors agree to respond to occasional emails from the Family Faculty, return paperwork in a timely fashion, attend one lunch meeting with their fellow mentors in late summer and be in immediate contact if they have any questions or concerns about their role or experience.
- Trainees are matched based on transportation needs. Most of our trainees do not have cars and depend on public transportation, so we match them with mentors near a bus or train stop). We also consider pets and allergies matching and try to match trainees with a family whose child experiences a condition with which they are less familiar. For example, we would not match the audiology trainee with a child with hearing loss.



Note: The Family Discipline Trainee is not assigned a Family Mentor. They are assigned a Health Administration mentor.

Additional Information

We ask LEND Trainees what they liked and didn't like about their Family Mentor Experience each year. They had suggestions for making it better. Here is what they requested the Family Faculty impart to the Mentors ahead of their first meeting:

- Take the lead on what we will do. Suggest days that work for you then we will work together to confirm the plan.
- Please introduce us to everyone in the house if they are there. It feels odd to have someone nearby listening to us that I haven't met.
- Try not to forget we are coming because it's a little bit embarrassing for us!
- We are ok talking about ourselves as well, so ask us questions if you like.
- If you take us to an IEP, we cannot sign as a member of the IEP team.
- We aren't allowed to answer any clinical questions.
- We are not supposed to focus on your child's condition or disability, but we would like to meet them and hang out with the WHOLE family if possible.
- Don't be shy. When a mentor seems like they don't know why we are there, it is a little embarrassing for us.
- Each year bumps sometimes arise with mentors, so we stress these nuts and bolts in the summer orientation meeting:
 - Stipend Form due within one week! No one gets their stipend until everyone submits.
 - Need a current photo of you with or without your child/family.
 - May I text you? Are you ok if we use a group text?
 - Can you serve your mentee alcohol? Sorry, no.
 - Can you leave your mentee alone with any member of your family? Sorry, no.
 - Can your mentee ride in your car? Yes!
 - Can they drive your child? No!
 - Can you let your personal support worker substitute for you on a visit? No!

Oregon LEND contact information:

Tamara Bakewell, Family Faculty

Email: bakewell@ohsu.edu

Website: <https://www.ohsu.edu/lend>



LEND Pittsburgh

One of the components of the LEND Pittsburgh curriculum for developing an understanding of the perspective of family members is the Families as Mentors (FAM) program. In this experience trainees become acquainted with a family who has one or more children with a disability/chronic health condition by visiting them at least two times in their home and/or in the community. Trainees are told to take off their “professional hat” while interacting with the family members. Through the FAM program, students have an opportunity to learn about one family by spending time with them.

Who

Families in the FAM program is referred through a variety of means. Some have been participating in the program for a number of years. Some families come to us after attending our LEND Clinic, and others have volunteered after the parent was a Family Trainee.

Additionally, families are referred by service providers in our community who are familiar with the FAM program (i.e. through the Down Syndrome Clinic, Sickle Cell Disease Clinic, Autism Network).

When

The LEND Pittsburgh Families as Mentors (FAM) program typically initiates in October, after trainees' acclimation to the LEND Pittsburgh curriculum. Trainees commit to meeting three to four times over the course of their training. Communication via email, phone, and/or text messaging helps trainees and their matched FAM schedule time together.

What

- Students are assigned to a family that is “different” in some way from their own family. Many of our families come from underserved populations in the greater Pittsburgh area, some include children raised by extended family members, and some have included families of gay/lesbian parents.
- Assignments are often made based on the family’s preference for visit times (e.g. in the evenings or on weekends) and student transportation needs are also considered.
- Students track all communication with the family, including attempts to reach them, visits scheduled, and visits attended.
- A LEND faculty member interacts with the students regarding their visits.
- Periodically throughout the year, time is spent in LEND didactic sessions for students to share their experiences with the overall group of trainees and faculty.
- After each visit, trainees complete a reflection where they give a brief description of how they spent time with the family. The major focus of the reflection is on the ideas, feelings, and questions they have as a result of spending time with the family.



Where

Typically, LEND Pittsburgh trainees meet with their FAM in person at locations of the family's choosing, as they endeavor to authentically show trainees what everyday life is like with disability present. Trainees have met with their FAM at the family home, playgrounds, church, doctor appointments, and more. More recently, due to the COVID pandemic, FAM meetings have been virtual. This has led to much creativity by trainees as they attempt to engage as much as possible with families. Trainees and their FAM have played games online together, read stories together, looked through family photos, and other virtual ways to connect and build rapport.

Additional information

The primary challenge of this program relates to the busy lives of family members and our trainees. When we originally developed the program, the expectation was for trainees to meet with the family five times across the academic year. However, it became clear that it was very difficult for family members to accommodate that schedule. Similarly, the trainees' schedules are often limited due to their academic and clinical education schedules in their degree programs. We gradually decreased the number of visits expected and this year moved to two visits which is realistic for the families and for the trainees.

Because our LEND Family Trainees already have the personal experience of living with a family member with a disability, rather than being matched with a FAM family, these trainees are matched with a community leader who is also a family member of an individual with a disability. The family trainees fulfill the same obligations as other trainees (i.e. two visits, reflections etc.) while receiving guidance from their community leader mentor on how they might best utilize their personal experiences in a leadership capacity. The mentor leaders are identified through faculty connections and referrals and Family Trainee alumni who have moved into community leadership roles also serve as mentors.

LEND Pittsburgh highly values the family perspective and incorporates it in a variety of additional avenues. First and foremost, LEND Pittsburgh Family Trainees follow a parallel curriculum as trainees in other disciplines and participate in all didactics and clinical activities. Other ways in which the family perspective is integrated within the curriculum include a family panel in our Leadership I course, family trainee presentations in our Leadership II course, didactics provided by the family faculty member, and family trainees consulting on all clinic cases, just to name a few.

LEND Pittsburgh contact information:

Dori Ortman, Family Faculty, Family/Advocacy Training Director, Clinic Coordinator

Email: dori.ortman@chp.edu

Website: <http://www.lend.pitt.edu/>



RILEND Program

The RILEND experience provides trainees an opportunity to gain insight and perspective into the lives of families with children with developmental disabilities. Our goal is to help fellows and trainees gain a better understanding of a disability beyond the typical textbook experience. The objective is for our Fellows/trainees to reflect on this experience when they move into their professional careers and to better support individuals and families.

During COVID pandemic restrictions, we adjusted our entire curriculum protocol to place family and self-advocate experiences firmly at the center of all our didactic conversations. Our family trainees have also been instrumental in driving the delivery of the presenter's information.

Who

- Families within Rhode Island - Long-term trainees
- Rhode Island Parent Information Network, The Autism Project, Rhode Island Department of Health, and RI Executive Office of Health and Human Services

When

- Minimum of 10 hours throughout an academic year per fellow/trainee from September- May. This will change when we go back to in-person or hybrid.

What

- The experience gives trainees a glimpse into a family's daily life.

Where

- Due to COVID precautions, the program occurs during regularly scheduled LEND weekly trainings and virtual meetings as requested.

Rhode Island LEND information:

Kathryn Lowney, LEND Coordinator

Email: Kathryn.lowney@lifespan.org

Website: <https://www.lifespan.org/centers-services/developmental-behavioral-pediatrics/rhode-island-leadership-education>



University of South Dakota LEND

The experience of being a parent or family member of an individual with a developmental disability cannot be taught. Family members share their perspectives impacted by culture, traditions, circumstance, and community. This shared knowledge is critical to developing authentic parent-professional partnerships, successful care plans, and effective policies and practices.

Who

- Mentor families with lived experience supporting a child or family member with congenital or acquired disability, representing the diversity of the state/region, typically reside in South Dakota or bordering states and have advanced in their parent journey to be effective advocates in the community or systems level.
- LEND trainees are assigned a mentor family with optional participation by the second year, self-advocate, and family trainees.

When

- Mentor families and trainees are assigned a minimum of eight hours of “visits” from October through April, as agreed upon by both parties.
- Monthly check-in visits are encouraged.

What

- LEND trainees and mentor families are provided written guidance on expectations before beginning their experience.
- Discussion of the mentoring experience is held during LEND classes early in the year to support and prepare trainees for a successful experience.

Where

Mentor family/trainee interactions include in-person, over the phone, virtual, home visits, therapy sessions, health care providers, IEP meetings, recreational or community activities/outings, and more.



How

- Mentor families are solicited through the state's parent center (Parent Training and Information Centers and Family to Family Health Information Center), current/previous LEND parent trainees, and mentor families. Mentor families frequently serve this role for multiple years.
- Brief information on family and child characteristics is posted via a Sign-Up Genius for trainees to self-select their mentor family on a first-come, first-serve basis. Trainees are encouraged to expand their experiences and comfort level when selecting a family.
- Mentor families and trainees are linked (generally via email) by the Family Discipline Head, who can assist with any barriers.

Additional Information

The Family Discipline Head may intervene to assign individually recruited Mentor families to LEND trainees who experience barriers to interacting with their families, with transportation-related barriers most frequently cited.

University of South Dakota LEND contact information:

Lisa Sanderson, Family Faculty

Email: lsanderson@sdparent.org

Website: <https://www.usd.edu/medicine/center-for-disabilities/lend>



Center for Disabilities



Utah Regional Leadership Education in Neurodevelopmental Disabilities

The Utah Regional LEND includes Idaho, North Dakota, Wyoming, and Montana. As a participant in the Project, the family is matched with a URLEND trainee. They will play a key role in providing the foundation for the assigned trainee to gain critical knowledge about the day-to-day aspects of living with a disability that will complement the learning the trainee obtains through URLEND educational sessions, materials, and clinical experiences. For the Family Mentorship Project, the family describes the experience of raising a child(ren) with disabilities or special health care needs. They also share their experiences in working with professionals from a variety of disciplines, the logistics involved in accessing educational, medical, and community resources, and the responsiveness of these service systems to their family's unique needs, desires, and culture. Through a series of observations of the child and family, the trainee will see real-life examples of how the family works with their school district, health care providers, and other formal support systems. The trainee will also have the chance to observe how the child(ren) with disabilities and special health care needs is included as a member of the family and community.

Who

- URLEND Core Faculty in all five states
- Parent and disability information and support groups
- Family and Self-Advocate Faculty
- Former URLEND trainees

When

- The required time is over the course of an academic year, with three visits from September to March.
- Trainees and families meet to schedule their visits together. We highlight to the Trainees that flexibility is a significant part of this assignment due to the unknowns (sickness, hospitalizations, behaviors, etc.) that the family may have come up at the last minute.
- The experience gives trainees a glimpse into the day in the life of a family.
- Trainees consider the family they are matched with as they are in their didactic seminars, leadership projects, clinical observations, and other assignments, including but not limited to policy and legislative activities and discussions. They are encouraged to reach out to their family to get their perspectives on any topics in the didactic seminars.
- Trainees are to do a reflection paper after each visit and do an overview of lessons learned at the end of the year with their cohort.
- The Family Faculty present in a didactic session at the first of the year to explain the Family Mentorship Program (FMP) and includes a Q&A session.



Where

- Virtual, in the home and community setting.
- The preferred method is “in-person meetings” but of course we were virtual the last year and it helped us expand to families that lived in a more rural area of the states.
- We ask the family to host one meeting in the home for trainees to get to know the family, the second one either in a school or medical setting, and the third in a community-based setting such as a recreational activity.
- These are merely suggestions as we have the family lead what they would like to share with their assigned trainee.

How

- Families are recruited from past participants, support groups and professional partners.
- When recruited, families are given a Family Mentorship Guide to give them an overview of the program and the expectations from both the trainee and their family.
- Both Families and Trainees fill out an information form providing demographic information. The form asks about interests, allergies, etc. that the trainees have in an effort for the Family Faculty to match them with a family that has some areas in which they are interested in learning about, such as the transition to adulthood, early intervention, specific intervention therapies as examples.
- Families receive \$50 for each of the visits for a total of \$150.
- Trainees and families are provided with a list of guiding questions to stimulate conversation if needed.
- Outside of the visits, we have additional families that are also paid a \$50 stipend to join in on didactic sessions to give their expertise and experience as well as co-lead on some presentations.
- We also invite families to be consultants on leadership projects. They get a stipend based on the amount of time agreed upon with Family Faculty and program management.

Utah Regional LEND contact information:

Joan Liquin, BS, Program/Trainee Coordinator

Email: joan.liquin@usu.edu

Website: <https://www.urlend.org/>



Virginia LEND

The purpose of the VaLEND's Family Mentorship Experience (FME) is to organically grow the awareness and knowledge of professionals working with families with children who have neurodevelopmental disabilities on their day-to-day life experiences. The goal of the program is for the trainee to experience an emotional growth arc as a result of the exposure to the variety and diversity of special need family dynamics, needs, requirements, struggles, etc. over a 6-7-month period experience that deepens their empathy and compassion for the families they will eventually support. The longer-term goal is that this compassionate understanding will spread exponentially as they work with more and more families, professionals, and institutions.

Who

The VaLEND at Virginia Commonwealth University in Richmond, Virginia. Most of our trainees live in the Richmond area, but we do have some participating remotely from other state regions. Our FME families are primarily live in Richmond/central Virginia. Still, through outreach to other Universities and support organizations such as regional Arcs, FME families are found geographically as close as possible with the trainee from their same region. Even though we began virtually in 2020, many families and their trainees felt comfortable enough to meet in person (following established safety protocols). Primary staff includes the Family Mentorship Coordinator, LEND director and assistant director, and office manager.

When

Typically, the VA LEND FME lasts roughly seven months, from September to early April. It is bookended by fall and spring picnics attended by the FME families, LEND faculty and staff, and the trainees participating in the FME. The trainees meet approximately two hours/month with in-between communications via email, phone call, and text.

What

- Trainees are shown a presentation in mid-August that provides an overview of the FME, expectations, timeline, and requirements and introduces several families to them through pictures and a brief introduction bio.
- The trainees are assigned soon after this presentation to their FME family.
- Assignments throughout the FME include submitting journal entries at three different intervals throughout the FME that offer a reflection of what the meeting was like, how the trainee felt about it, where they met, etc.; creating two short Flipgrid videos that provide a different, more casual medium to discuss the meeting and their feelings about it; making video responses to two other trainee videos and participating in the picnics (in a typical year) unless unable to. Double click on image below to access a copy of the [2021 Trainee FME Manual](#).



Where

- Due to COVID-19 pandemic restrictions, all in-home visits, Individualized Education Plan (IEP) meetings and therapy sessions were virtual.
- In-person visits took place at an outdoor dance recital, a horseback riding lesson, a park, a walk in the family's neighborhood, etc.
- In a typical year, all visits take place in person and include birthday parties and doctor visits, music recitals, visits to the museum, etc.

How

Many VaLEND FME families are return families! One family had been with the program for almost 20 years as their special needs family grew. Families are also recruited via special needs support groups, social media, word of mouth, outreach to state agencies and organizations such as the Virginia Arc, the Autism Society of Central VA, and the Down Syndrome Association of Greater Richmond.

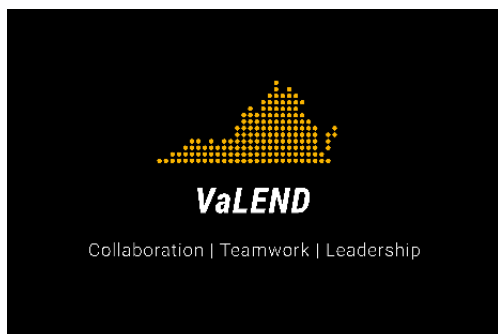
Trainees are paired with an FME family based on a variety of factors including, geographic location, pet allergies, likes and interests, background information such as school attended or state grew up in. If requested, a trainee is matched with a family whose child has a particular disability or special health care need that aligns with their discipline. For example, a trainee studying genetics may be paired with a child with a genetic disorder, autism with autism, etc. (Note: Autism fellows must be paired with an autism family). Otherwise, trainees are paired with families based on the previously stated factors.



All visits are conducted virtually and will continue to be so until our host institution (Virginia Commonwealth University) allows in person visits. For the first time, in 2020-2021, VA-LEND families received an honorarium. However, financial compensation is not guaranteed and, so, is not noted in the FME Family manual. However, financial compensation is not guaranteed and, so, is not noted in the FME Family manual.

Additional Information

Occasionally, we share information with the trainees such as articles, trainings, events, and state/federal legislation that are pertinent to their LEND training. Reading or attending any event, training, etc. is voluntary on their part. Trainees are welcome to continue a relationship with their FME family even after the FME has ended.



VaLEND contact information:

Kate Flinn, Family Mentorship Coordinator

Email: flinnk@vcu.edu

Website: <https://virginalend.partnership.vcu.edu/>



University of Washington LEND Families as Mentors

This experience typically pairs interested trainees with community families for a personal, out-of-the-clinic experience to expand the trainees' understanding of a disability beyond the textbook experience. During COVID restrictions, we adjusted our entire curriculum protocol to place family and self-advocate experiences firmly at the center. As a larger program with 30-40 trainees, including five Family and three Self-Advocate (SA) trainees, we created small group “squads” with at least one Family or SA trainee in each group. These squads worked together weekly or bi-weekly throughout the academic year. Our three-quarter system lends itself to areas of focus centered around individual lived experiences: Fall - Book Club on “The Parent Professional Partnership, a Dance that Matters;” Winter - “Telling Your Story” Advocacy, and Spring - Beyond pediatrics: Transitioning to adulthood. In addition to these focuses, many seminars throughout the academic year included SA and Family reflections of lived experiences, for example, Applied Behavior Analysis (ABA) Principles and Reflections from SA. Amending our entire curriculum for a virtual year has been positive for Families as Mentors. All 30+ trainees experienced the benefit of working closely with family and self-advocate trainees rather than the self-selected 15-18 trainees in the past years.

Who Benefited from our Expanded FAM Program

- This expanded format deepened the experience for the entire trainee cohort.
- Our Family and Self-Advocate trainees also gained facilitation and leadership skills in the small group setting.

When

- During regularly scheduled LEND Seminars
- Individual “Squad” meetings
- Independent reading time for book club and access to film
- Group “Dance Party” for book club with the author and “Watch Parties” for the film

Where

- Virtual - in-home University of Washington protocol during COVID for all Academic programming



How

- Fall Quarter
 - Squad meetings met twice monthly during the fall quarter to build rapport with stem questions to facilitate discussion
 - Book Club required reading *The Parent Professional Partnership, a Dance that Matters* by Janice Fialka.
- Winter Quarter
 - Squad meetings met 1-2 times monthly as needed for seminar assignments, gaining a direct family and self-advocate perspectives
 - Workshops and seminars on advocacy entailed creating a policy “ask” connected to direct lived experiences, such as the need to fund universal preschool, access to mental/behavioral health, and the need to adjust supplemental security income levels.
- Spring Quarter
 - Squad meetings continued to meet 1-2 times per month
 - Watch Parties Facilitated by Family Discipline Sharing *Intelligent Lives* by Dan Habib, including 30-minute discussion opportunities in small groups.

Additional Information

We plan to continue our Interdisciplinary squad protocol and adjust the workshop/seminar curriculum as COVID restrictions allow in future years. We will offer the Community FAM program, matching interested trainees with families in the community as the families' comfort and availability allow.

UW LEND contact information:

Susan Adelman, OT, Discipline Lead

Email: adelms@uw.edu

Website: <https://uw-ctu.org/uw-lend/>



Westchester Institute for Human Development

The overall goal of the WIHD LEND Family Mentorship Experience assignment is to learn from another family about the impact of having a child, adolescent or young adult with a disability, their experiences working with professionals from various disciplines, and the responsiveness of service systems to the family's needs and desires. Another goal is that trainees will have an opportunity to hear about how families work in partnership with their school district, health providers, or other formal support systems and to gain insight into areas they may not have previously explored with another family.

Who

We always try to include many of our former LEND Family Specialists that are part of our listserv and their families when seeking families who want to serve as Family Mentors.

All our trainees take part in the assignment; however they work with different guidelines depending on if they are a "Family Specialist" trainee or other disciplinary trainees in the LEND program.

When

When we were pre-Covid, we had our trainees schedule two visits with their assigned mentor families. One visit would be at the family's home, and the other would be out with the family in the community. Due to the restrictions imposed by Covid this past year, we had the trainees schedule two "virtual visits" with their assigned family via Zoom. The first visit for the family to share their personal story. The second as a follow-up when the trainees had time to reflect on all they heard and to ask additional questions of the family. Trainees and families schedule their own meetings.

Trainees are assigned their Mentor Family in December/early January and then schedule their two visits between then and the next several months. Visits occur with enough time to be prepared to share back to their fellow trainees in a session scheduled for early April.

What

Trainees are assigned to a "mentor family" in late December/early January. Families and trainees each fill out contact information, special requests and information (i.e., pre-Covid a trainee might ask to be assigned to a family with no cats due to allergies or ask to meet with a family no further than 30 minutes from their home).

- Families are sent a "Family Mentorship Experience visit interview guide" to review the types of information they should cover when meeting with their assigned trainee, virtually or in person.
- All trainees are required to complete an "Impressions and Reflections" document upon completion of their second meeting with the family. These documents get posted on LearnDash



Moodle, which is our learning platform. Again, suppose a trainee is a Family Specialist. In that case they need to fill-out the “Family Specialist” version of the “Impressions and Reflections” form. If they are any other disciplinary trainees, they fill out the form designated for them.

- In early April, we have our “Family Mentorship Experience” assignment share-back session. We divide the trainees up into two groups—this year two, “virtual groups,” with half going with one LEND Family Faculty member and the other half with another LEND faculty member. Each trainee gets 5 minutes to respond to questions from the “Impressions and Reflections” form and 2 minutes for questions and comments by fellow trainees. This should be an informal, non-PowerPoint presentation. Before the share-back, trainees are reminded about maintaining confidentiality in their written “Impressions and Reflections” form submitted on Moodle and in their oral presentations.
- **The questions the trainees are asked to share-back on are as follows:**
 - Trainees identify one issue in which the family has advocated for themselves or their family member to address their concerns; and who were their family advocacy partners.
 - How do you think that this experience may change your approach to working with families of children, adolescents, or young adults with disabilities through the lifespan?
- **For Family Specialist trainees:** How do you think this experience may impact your own future family advocacy and disability leadership roles?
- All trainees are asked to send either a thank note to the family they were matched with or thank the family by phone.

Where

In-person, the Family Mentorship experience assignment takes place in the family home for the first visit and the community for the second visit. Virtually, both the first and second meetings take place via zoom.

How

Pre-Covid Mentor families and trainees were matched based on geographical locations. Therefore, we tried to match trainees with families that lived within a 30-minute driving radius from them if possible. During Covid, we did not need to worry about this issue. Therefore, while we missed having the opportunity for trainees and families to meet in-person, the matching was more accessible due to flexibility and not being constrained by where individuals live.

WIHD LEND contact information:

Clara Hannum, LEND Program Coordinator

Email: channum@wihd.org

Website: <https://www.wihd.org/training/lend/>



Wisconsin LEND

The WI LEND Family Mentor experience is designed to provide trainees experiences and insights into the daily lives of families with children with disabilities. Trainees are encouraged to listen deeply to their Mentor Family's story so that they can learn to identify the family's preferences, values, and culture. These experiences and insights help trainees practice and develop their family-centered skills so that they can provide and improve supports, services, and systems of care for children with special needs/disabilities and their families by bringing a family-centered focus to their practice, teaching, research, and advocacy.

Who

- Families within Wisconsin, based in the Madison and Milwaukee areas
- Long-term and the occasional Medium-term trainees
- Family Mentor Coordinator

When

- A pair of trainees are matched with a Mentor Family. The trainee pair and Mentor Family meet in person four times over the first four months of the training year (with COVID, we reduced this to three visits over Zoom and moved from Fall semester to Spring).
- Trainees and families work together to schedule meetings at times and places that work for both.

What

- The Family Mentor experience occurs in the fall semester allowing trainees to draw on their learning from this experience throughout their training year and for specific LEND assignments (e.g., legislative visit).
- Trainee pairs meet with their Mentor Family once in the family's home, two times in the community, and either in the community or the family's home for a wrap-up visit (With COVID, we moved this activity from Fall to Spring semester, converted all visits to virtual, and only required three visits.)
- Before beginning the Family Mentor experience each trainee reads and writes a reflection on Every Family Has a Story and participates in an active listening exercise (see [Every Family Has a Story](#) and [Every Family Has a Story Reflection Guide](#)).



- Each pair of trainees develops a Care Map either for or with (family's preference) their Mentor Family (see [Care Mapping: A How-To Guide for Patients and Families by Rich Antonelli, MD, MS and Cristin Lind, BA](#)).
- Each pair of trainees creates something they share with their Mentor Family (see [Closure Guidance](#)) to practice creating closure with a family. Their closure creation reflects something unique to their Mentor Family and includes a brief description of what each member of the trainee pair most gained from or appreciated about their Mentor Family and their time with them. The closure creation is designed to acknowledge the important role their Mentor Family has played in their professional and personal life and thank them for graciously (virtually during COVID) opening their lives and living rooms to them.
- Trainees are encouraged to reflect on each visit in whatever way makes sense to them (see [Reflection Guide](#)).
- Each trainee meets one time with the Family Mentor Coordinator to process their experience.
- Trainees engage in small and large group discussions of their reflections on their Family Mentor Experience as a wrap-up activity in seminar.
- Family Mentor coordinator compiles trainee's descriptions of most appreciated and most impactful learning into a Thank You letter that is shared with all trainees and Mentor Families so that everyone can see the breadth and depth of learning and teaching that occurs through Family Mentor.

Where

- In non-COVID years, Madison-based families and their trainee pairs are invited to a Family Mentor Kick-Off event (pizza party) at the Waisman Center (where many of the families receive services and the LEND program is housed).
- 1-2 visits: in the family's home (virtually during COVID).
- 2-3 visits: in the community (virtually during COVID) which could include appointments (therapy, doctor, school-based), recreation or leisure activities, errands, sibling's activities, etc. This helps trainees gain exposure to a broad range of family's daily activities.



How

- Families are recruited from a variety of sources, including past Family Discipline trainees, families known to LEND or Waisman Center Clinic staff, referrals from partner agencies, at family leadership events, and responses to flyers.
- Trainees complete several forms to aid in matching them with a family that will meet their training goals for the Family Mentor experience.
- Families complete a Family Mentor Application and Mentor Family Information form. Information from these forms and an interview with the Family Mentor are used to create a bio for the family that is used to help match trainees and families.
- Trainee pairs schedule their visits directly with their Mentor Family.
- Families are mentored/supported by the Family Mentor coordinator. The Family Mentor coordinator checks in with families once a month.
- Families receive a \$200 stipend for their participation.

Additional Information

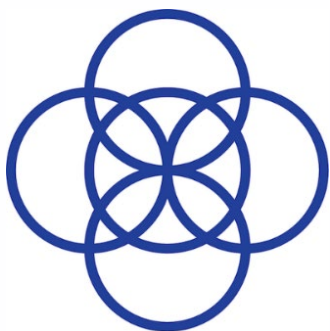
Trainees are provided with a list of guiding questions. However, they are not expected to stick to the guide and are encouraged to let the conversation flow naturally.

WI LEND contact information:

Gail Chödrön, LEND Training Director

Email: chodron@waisman.wisc.edu

Website: <https://wilend.waisman.wisc.edu/>



WI LEND Program

Wisconsin Leadership Education in Neurodevelopmental and Related Disabilities





Special thank you to Stephanie Coleman from Kansas LEND for her leadership in developing the LEND Family Mentorship Models.

This document is provided in partial fulfillment of tasks outlined in a cooperative agreement (#UA5MC11068) between AUCD and the Maternal and Child Health Bureau (MCHB). The contents do not necessarily reflect the views or policies of MCHB, the Health Resources Services Administration, U.S. Department of Health and Human Services, or the U.S. Government.

