



2021 LFDN Summit Day 2

Tuesday, September 28

3:00 – 6:00 pm ET

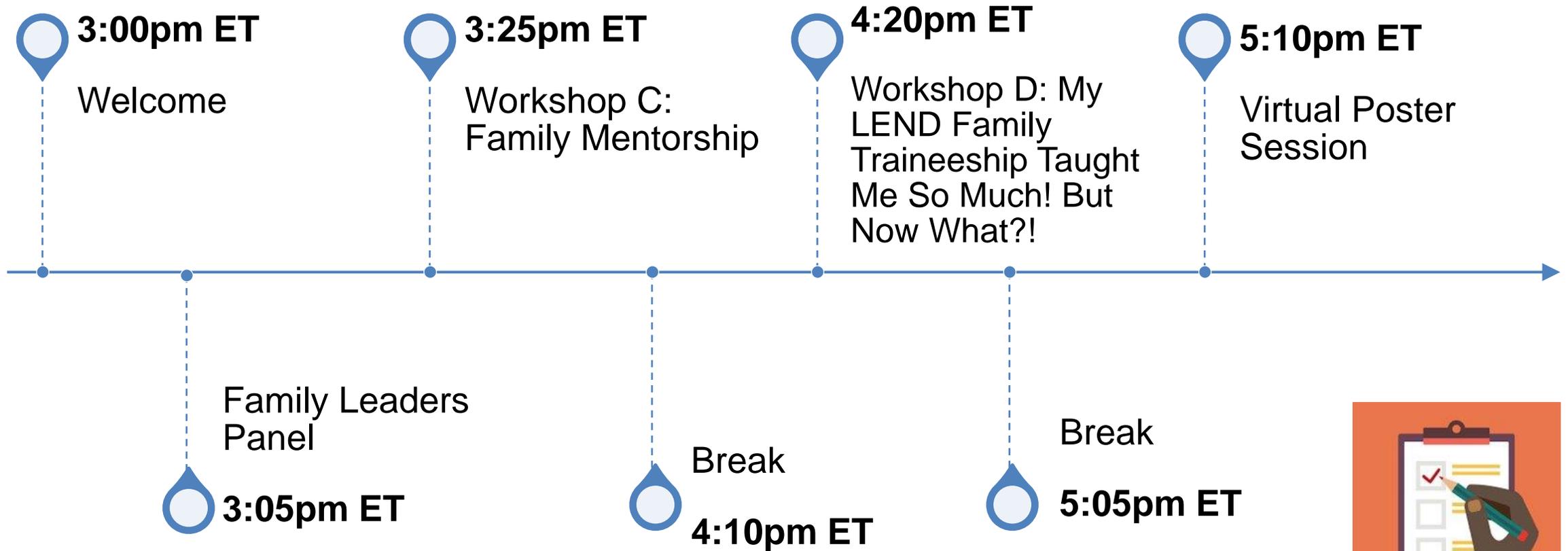


Housekeeping

- Ensure your name is displayed correctly in the participant list. You may also include program/org and preferred pronouns.
 - Example: Jackie Czyzia, AUCD, she/her
 - Hover over your name in the “Participants” box and select “More” → “Rename”
- Remain muted unless speaking
- State your name prior to speaking
- Live captioning is available
- Use chat box to introduce yourself!



Day 2 Agenda





Family Leaders Panel

Moderator: Fran Goldfarb (CA-LEND)



Panelists



**DeBorah
Bonet**
OK-LEND



Nita Chettiar
JFK Partners
LEND



Tiffany Clifton
NE-LEND



**Regina
Rodriguez
Sisneros**
JFK Partners LEND



Workshop C: Family Mentorship

Facilitators: Stephanie Coleman (KS-LEND)
and Kristin Mayleben-Flott (NE-LEND)



What words come to mind when you hear:

Mentor

Mentoring

Mentorship

Or Scan the
QR Code

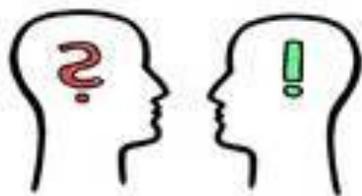


Enter your answers

here: <https://www.menti.com/yrou2vdshw>



MOTIVATION



GUIDANCE

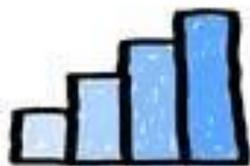


SKILLS

MENTORING



ADVICE



SUCCESS



POTENTIAL



Examples of LEND Mentoring Programs

Kansas

- Family Immersion Program
 - Virtual
 - Year-long
 - Informal Interviews
 - Assignments
- Parent-led LEND seminars

Nebraska

- Project DOCC
 - Formal Interview
 - Home Visit
- Parent Panels at LEND seminars
- Family-led discussions



Barriers & Challenges

- Recruitment
- Identifying Families
- Accessibility
- Family Confidence
- Time
- Acceptance of Child's Diagnosis
- Diverse Families
- Funding
- Technology
- Emotional Toll on Family & Trainees



Benefits & Successes

- Share Daily Life Experiences
- Share Joys & Successes
- Give back to the community
- Educate professionals on family perspective
- Empower Families
- Create future advocates
- Build trainees network of families and professionals
- Acknowledgment of the importance of family perspective
- Disciplines acknowledge family as part of team
- Family seen as leaders
- Family part of leadership team



Questions?



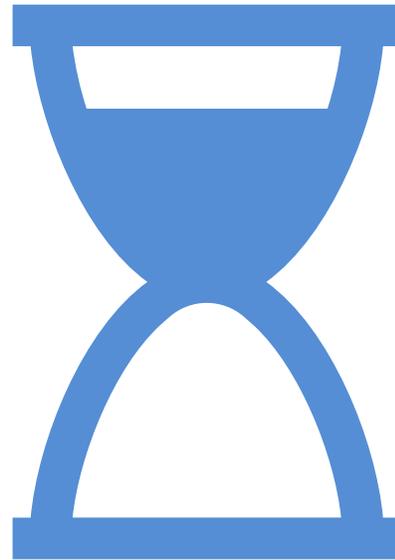
Q & A

Krisitin Mayleben-Flott - NE
kristin.flott@unmc.edu

Stephanie Coleman - KS
scoleman3@kumc.edu

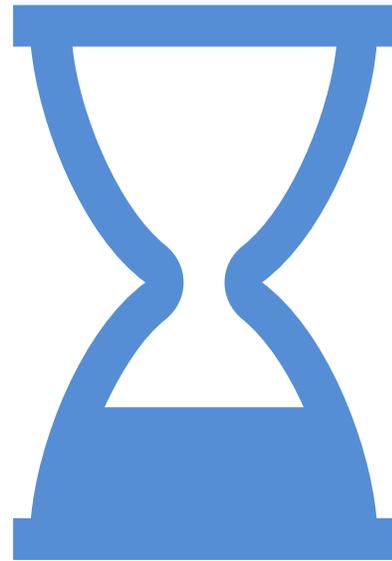


BREAK – 10 MIN





END OF BREAK





Workshop D: My LEND Family Traineeship Taught Me So Much! But Now What??

Facilitators: Angela Miney (UF),
Dori Cameron Ortman (LEND Center at Pittsburgh), and
Mark Smith (NE-LEND & UCEDD)



Opening Panel

Mark Smith, MS – Intentional Transitions

- Assistant Professor at the Munroe-Meyer Institute (MMI) at the University of Nebraska Medical Center
- Family Faculty in the MMI LEND program since 2003
- Helped develop the Family as a Discipline in the AUCD network
- Co-chairs the AUCD Family Support Special Interest Group

Angela Miney – Think Outside the Box

- Family Partner with the University of Florida Pediatric Pulmonary Center (an MCHB funded program) since 2006
- Began coordinating the Florida Family Leader Network in 2016
- Recipient of the prestigious Merle McPherson Family Leadership Award in 2021

Dori Cameron Ortman – The Power of Connections

- Family Faculty with the LEND Center of Pittsburgh since 2010, affiliated with the University of Pittsburgh and UPMC Children's Hospital of Pittsburgh
- Developed inclusive curriculum for LEND Family Trainees that closely parallels their clinical peers
- LFDN Steering Committee and chair of the "Life After LEND" committee

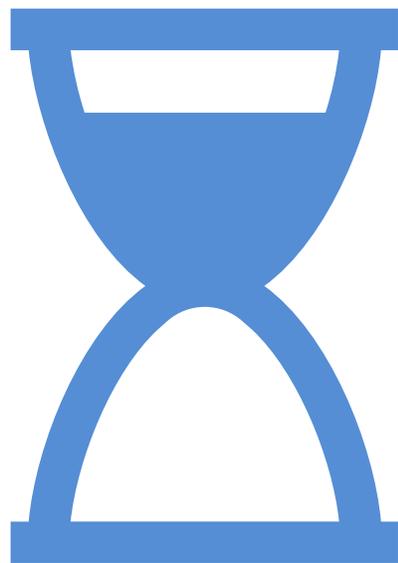


Breakout Room Instructions

- **Discussion Prompt:** Discuss ideas and possible strategies on how family trainees, with the support of their programs, can develop a clear plan for life after LEND?
 - What supports might be needed toward ideas/strategies discussed.
- Each breakout room should choose one idea/strategy they feel is the “best” and **one person will report out during wrap-up**

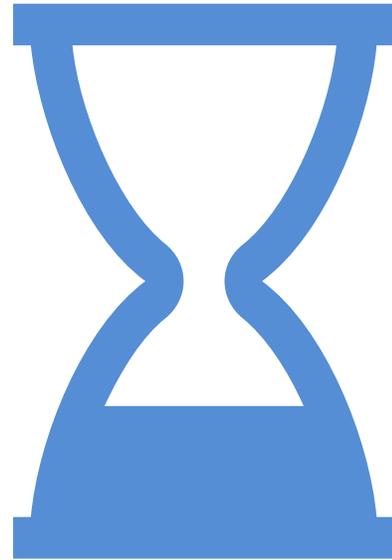


BREAK – 5 MIN



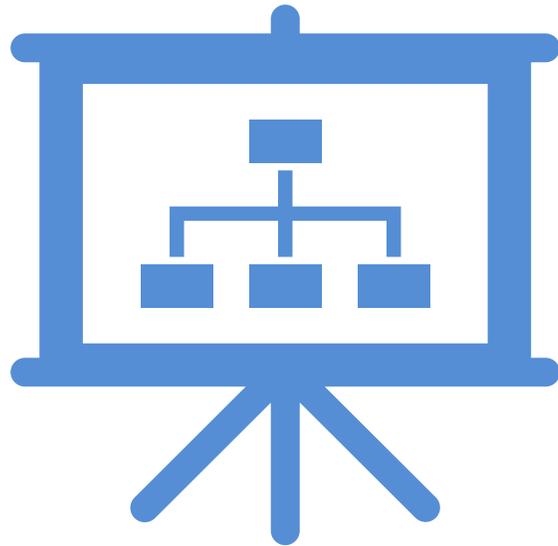


END OF BREAK





Virtual Poster Session





Virtual Poster Session

1. California LEND: Fran Goldfarb
2. Wisconsin LEND: Tim Markle
3. Oklahoma LEND: Wanda Felty
4. Rhode Island LEND: Jonna Mulvaney
5. LEND Center of Pittsburgh: Dori Ortman



CA-LEND

Fran Goldfarb, MA, MCHES, CPSP/ Family Support Discipline Director/ Los Angeles, CA



Program History

The CA-LEND program was founded in 1966 and is one of the oldest LEND programs. We piloted Family Support trainees in 1995. Based on this success, Fran Goldfarb was hired in 1997 to be the Family Support Discipline Director. Since then, we have had 44 Fellows and 2 Intermediate Trainees graduate from LEND.

The Family Discipline

- Siblings
- Parents
- 66% from Communities of Color
 - 39% LatinX
 - 33% White
 - 15% African American
 - 13% API

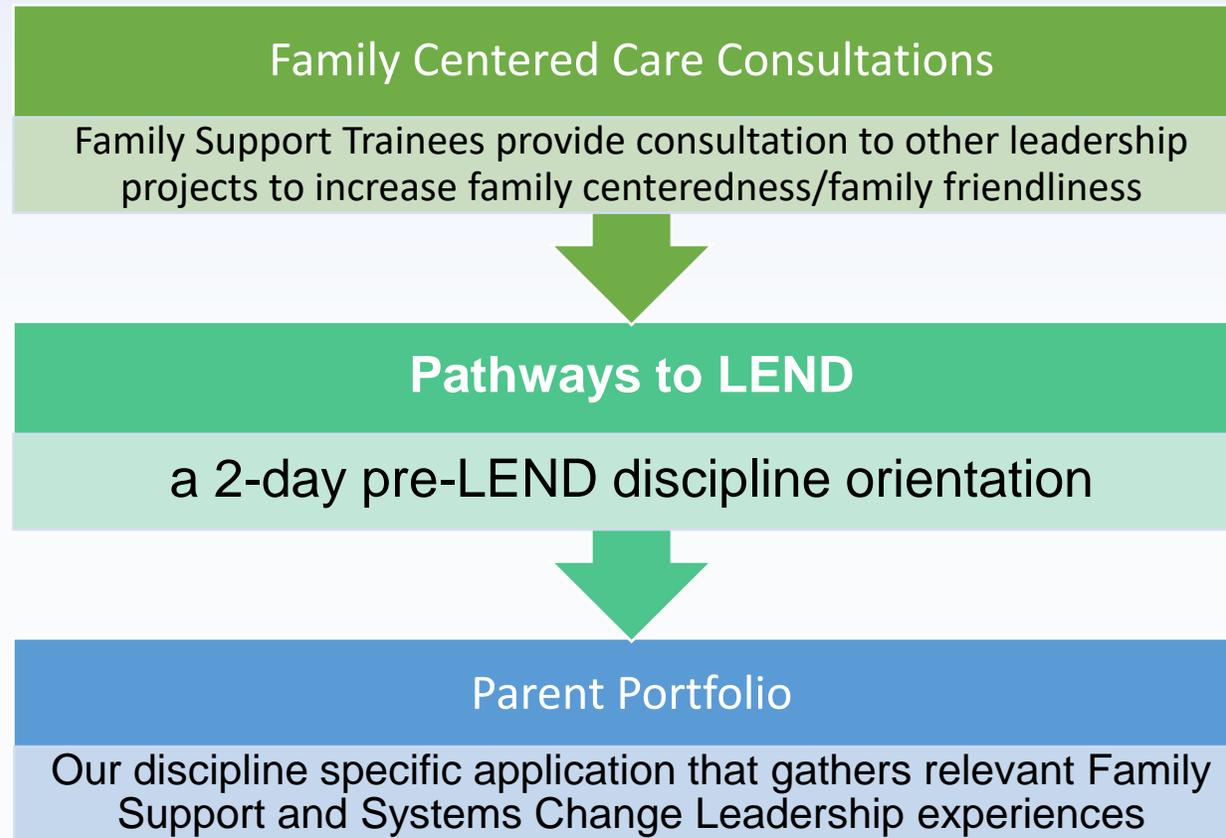
Program Modifications

Same requirements as other disciplines

Accommodations

- 2-year program
- Access to extra mentoring
- Editing of assignments
- Alternate Clinical Opportunities

Key Features of Your LEND Program



Qualifications

- No Educational Requirement
- Min. 4 years experience in Family Support or Systems Change Leadership
- Favor Fellows over short or medium term trainees

Opportunities for Growth

- No advanced degree- Pathways to LEND allows for pre-teaching some LEND activities
- Very Full Plates – Family Support Trainees do LEND over 2 years
- English as a second language – provide expanded opportunities for discipline mentorship
- Applicants don't understand the LEND program – LEND Family Support Discipline Information Meetings.

Contact

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fgoldfarb@chla.usc.edu
323 361-3831



WI LEND

Tim Markle, MA; MA/CS, Family Discipline Coordinator, Madison, WI



Program History

The WI LEND program is housed within the University Center for Excellence in Developmental Disabilities (UCEDD) at the Waisman Center, University of Wisconsin-Madison. WI LEND has been funded for over 50 years and included family faculty for years before the first family trainee in 2005. Overall, WI LEND offers training to 16 disciplines.

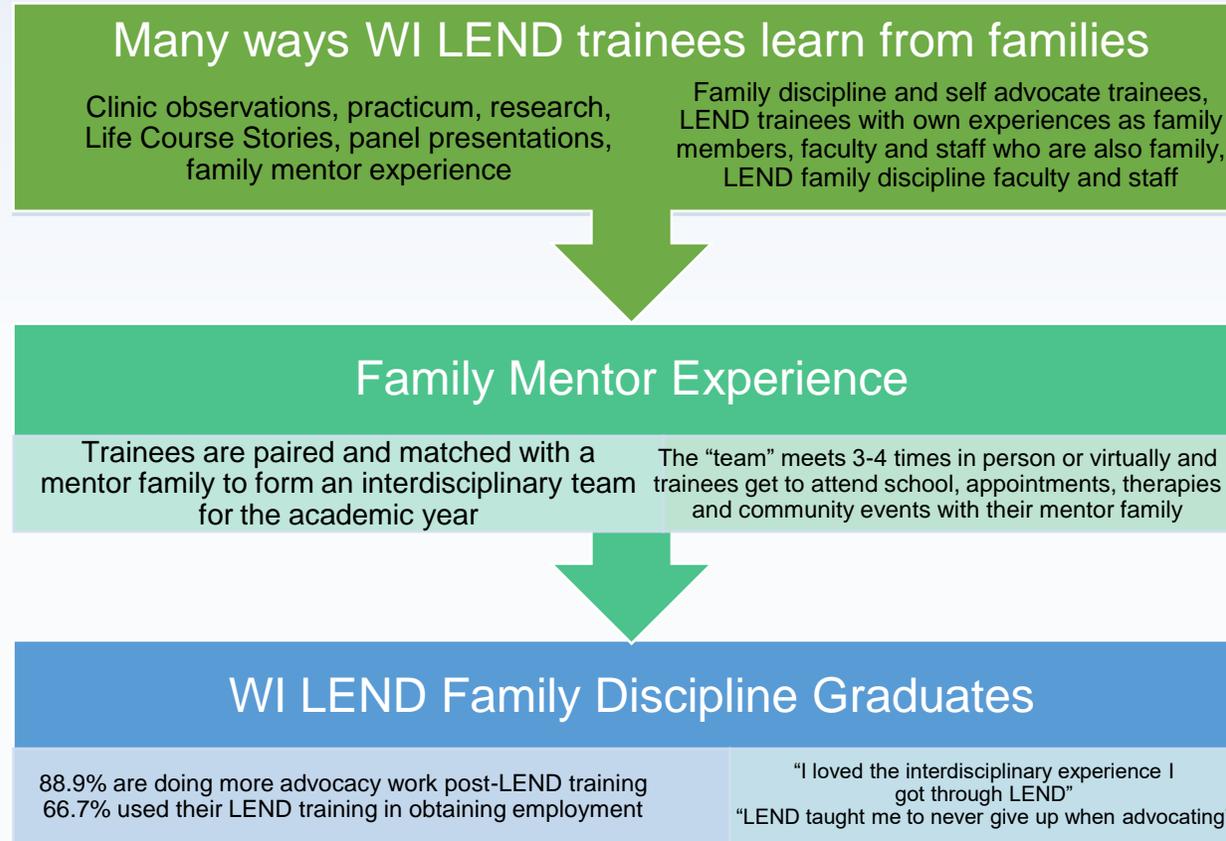
The Family Discipline

Family was represented through faculty for years and the program was originally designed for trainees in health fields. Once Gail Chodron became a family trainee in 2007, she eventually took on a leadership role and worked to evolve the curriculum to be more explicitly inclusive of all disciplines, especially family trainees. This paved the way for the program to include self-advocates.

Program Modifications

All WI LEND trainees complete the same training program. Trainees have the option of completing long-term training over 1-2 years, or they can be an intermediate trainee (focus on instructional components). Program can be adapted in other ways as needed.

Key Features of Your LEND Program



Qualifications

Family trainees do not have a specific education requirement. They must be the parent or family member of a child/young adult with an intellectual/developmental disability. It is recommended that family trainees have some experience in advocacy, but not required.

Opportunities for Growth

WI LEND has expanded from its home within the UCEDD and UW-Madison to include a second location in Milwaukee. This has helped to expand diversity, but there is room for improvement in this category. This second location has fewer disciplines represented, but family is one that has been included from the beginning.

Contact

Timothy S. Markle, MA; MA/CS
Family Discipline Coordinator
WI LEND
tmarkle@wisc.edu

Highlights from OKLEND

Program History

1994 The University Affiliated Program of Oklahoma, now Center for Learning and Leadership/UCEDD (CLL), in partnership with OU College of Medicine and Dept. of Pediatrics, wrote for the first LEND grant. The UAP hired a family member to serve as a content expert to assist in designing the curriculum.

Family Involvement

1995 - Present

Family Faculty/Staff involved in

- Creating of course curriculum
- Delivery of the instruction
- Design of practicum requirements
- Development of the course evaluation

Qualifications

No specific educational requirements.

Experience required:

- Advocating for their family member
- Experience supporting other families to navigate services
- Advocating for other families

Family Involvement from the beginning

A family member was a paid staff member participating in the writing of the original course curriculum. OKLEND has had a family faculty participating in the design, implementation, delivery and evaluation of the LEND program since the first year of the grant.

Family Mentorship Program

Family Life Experience
Family Advocacy – focus on family-professional partnerships

Family Discipline Trainee Expectations

All trainees work from the same course curriculum and requirements
All trainees receive the same stipend



OKLEND First Family Faculty and Trainee
Jan Moss, Family Faculty
Wanda Felty, Trainee in the Family Discipline

Trainees/Graduates

The OKLEND trainees and graduates from the Family Discipline represent the demographics of our state with representation from rural and urban areas along with Native American tribal affiliations and Hispanic ethnicity. Most are parents and one sibling.

Family Mentorship

A project out of the CLL/UCEDD and coordinated by Family staff member who is also the OKLEND Family Faculty consists of:

- OKLEND Family Mentoring practicum required for all trainees
 - Fall – Family Life experience
 - Spring - Family Advocacy
- Training for Family Mentors through pre- and post- meetings using feedback from trainee reflection papers

Contact

Wanda P. Felty

Community Leadership & Advocacy
Coordinator Core Faculty Mentor

wanda-felty@ouhsc.edu



Rhode Island Leadership Education in Neurodevelopmental Disabilities

Jonna Mulvaney, Family Discipline Coordinator
RI LEND, Providence, Rhode Island



Program History

RI LEND was established in 2016. In our first 5 years we recruited 70 amazing LTTs who represent the diversity of our state. Of these, 36% have been parents, family members or self-advocates with ASD or other developmental disabilities; 13% have been Hispanic, 13% black, 7% Asian, and 6% multiracial. RI LEND has a deep ongoing connection to our parent organization community partners including the RI Parent Information Network, the Autism Project & RI Kids Count..

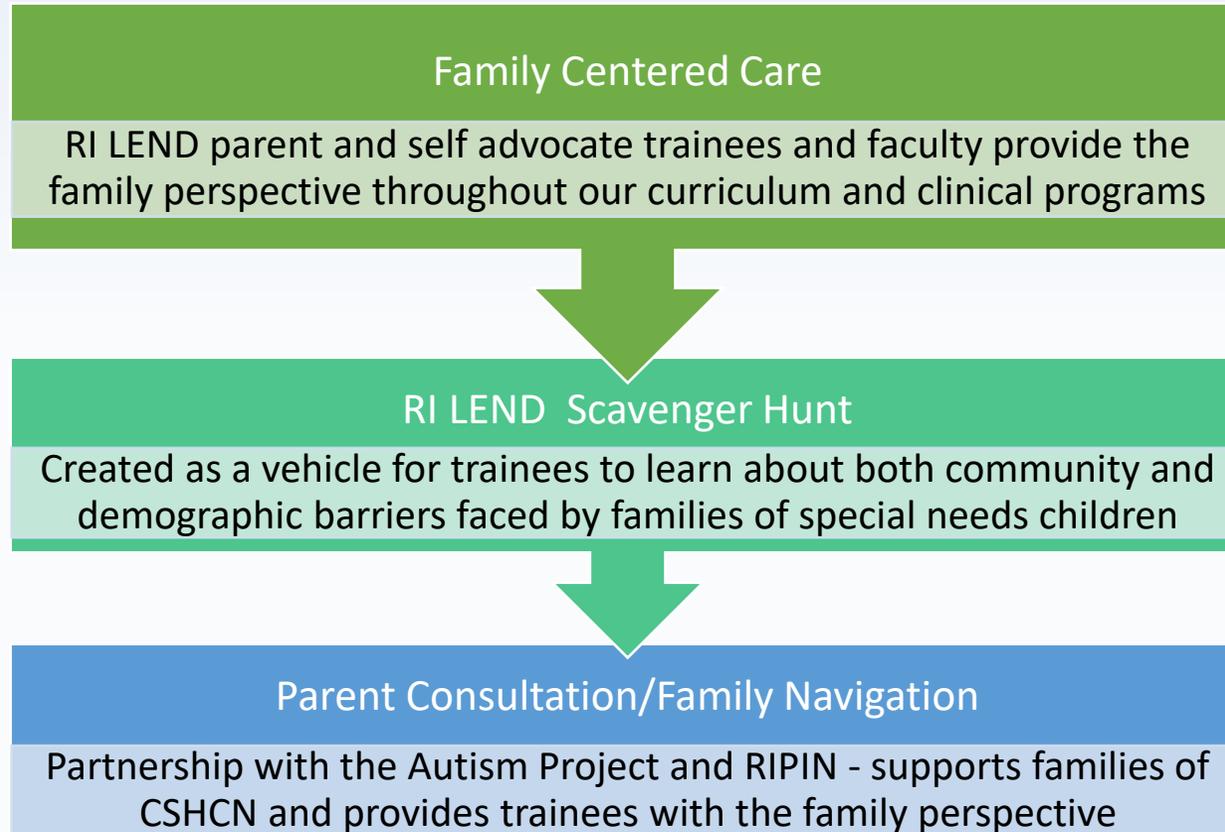
The RILEND Family Discipline Make-up

Many RILEND trainees fit more than one discipline. For example, one of our self-advocates was Hispanic, completing her Master's and Internship in Speech and Language Pathology and she used a wheelchair for ambulation due to a birth anomaly. Last year our self-advocate was competing his degree in political science and economics, was Black and had been adopted from Central America. He also had an ASD. While some of our trainees were in graduate programs or fellowship training during their LEND year, a significant number were also professionals working in the field. For example, last year one trainee was the parent and sibling of individuals with intellectual and mental health challenges, a nurse, an educator and was working on her doctorate in child development.

Program Modifications

Trainees in RI LEND's Family Discipline are provided access to extra mentoring, editing of assignments and alternate clinical opportunities. Virtual sessions have allowed those needing to stay home with their children due to covid full access to our program.

Key Features of the Family Focus of RI LEND



Qualifications

The major qualification for trainees in our family discipline and for self-advocate is their life experience. Trainees in other disciplines must be in or have completed Master's or Doctoral Programs.

Opportunities for Growth

- RI LEND's new Family Mentor Match will create real-life first-hand experiences for trainees to help them understand the challenges and opportunities faced from families of CSHCN.
- We aim to provide expanded opportunities for discipline mentorship
- Assist applicants to fully understand the promise of LEND program and what could come after graduation

Contacts

- Pamela High, MD. RILEND Program Director phigh@lifespan.org
- Shannon Dowd-Eagle PhD, Associate Program Director seagle@ric.edu
- Jonna Mulvaney, Family Discipline Coordinator. jmulvaney1@lifespan.org
- Kathryn Lowney program coordinator kathryn.lowney@lifespan.org



LEND Center of Pittsburgh

Dori Cameron Ortman, Family Faculty – Pittsburgh, PA

Key Features of the LEND Center of Pittsburgh

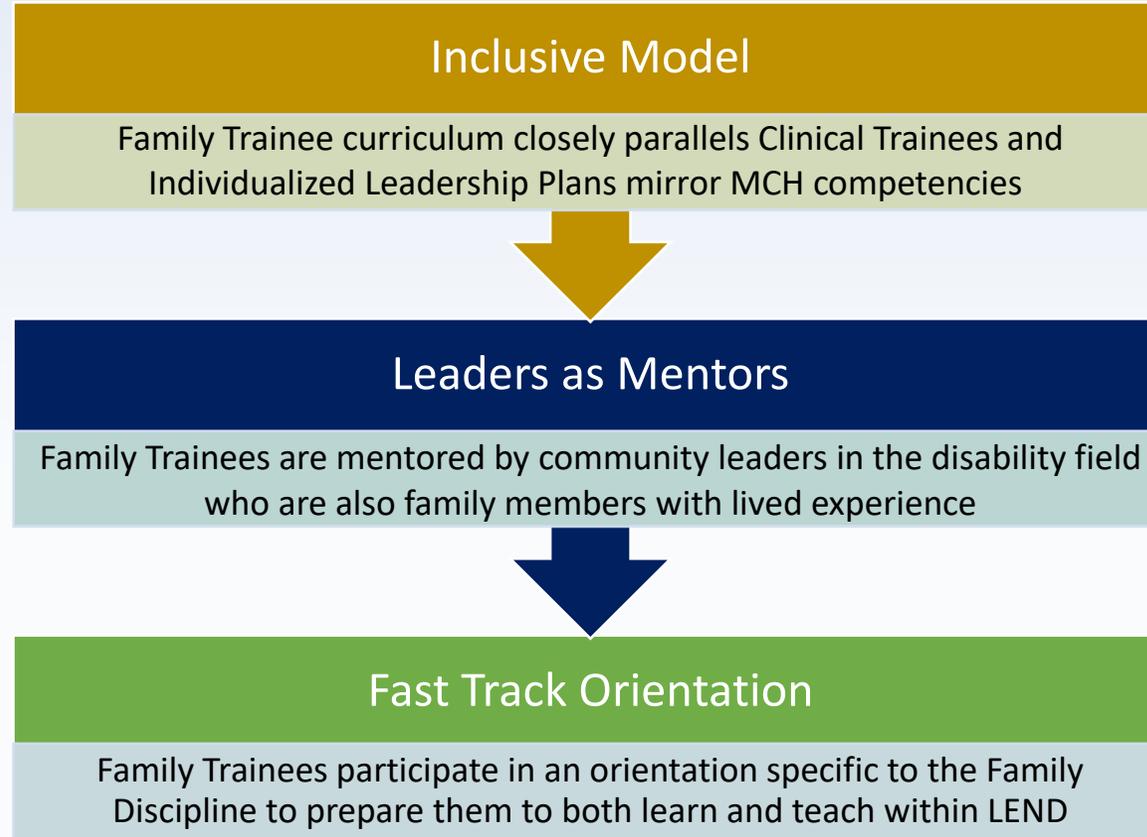


Program History

The LEND Center of Pittsburgh is affiliated with the University of Pittsburgh and UPMC Children's Hospital of Pittsburgh. LEND Pittsburgh was founded in 1996 with the mission of training the next generation of leaders who provide interdisciplinary, family-centered care to children with disabilities and their families with a special emphasis on underserved populations. LEND Pittsburgh continues to be passionate about this mission now and into the future.

The Family Discipline

After spending more than 15 years working with families and children with disabilities, Dori Cameron Ortman joined the LEND Pittsburgh team in 2010 to develop an inclusive training experience for Family Trainees. Since then, we have trained 18 Family Trainees from a variety of backgrounds and experiences. Trainees have included parents/caregivers and siblings of individuals with disabilities.



Program Modifications

- Opportunity to participate in a 2-year program
- Extra time given for assignments, as needed
- Clinic participation occurs in second term

Qualifications

- University enrollment not required
- Must demonstrate prior advocacy and leadership initiatives
- Goals of expanding reach in advocacy and family supports

Opportunities for Growth

- Short-Term Traineeship virtual opportunity for rural families and self-advocates – identifying and accommodating rural families
- Lack of service providers and supports due to pandemic making in-person training difficult for family trainees

Contact

Dori Cameron Ortman

Family Faculty/Family and Advocacy Training Director

Dori.Ortman@chp.edu

412-848-7323



Thank You!

Summit Planning Committee

- Stephanie Coleman
- Fran Goldfarb
- Wanda Felty
- Kristin Mayleben-Flott
- Tim Markle
- Angela Miney
- Jonna Mulvaney
- Dori Cameron Ortman
- Mark Smith

This would not be possible without...

- Panelists
- Poster Presenters
- Emma Fox, Former AUCD Staff Liaison
- AUCD
- MCHB

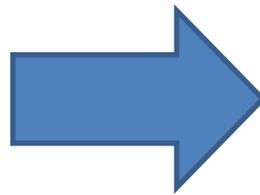




Evaluation Survey

- Thank you for attending Day 2 of the 2021 Family Discipline Summit!
- Please complete the following evaluation survey:
<https://www.surveymonkey.com/r/XGFKYCB>

*or scan the
QR Code*



- Workshop recordings, resources, and slides will be available within one week of today's meeting



Day 2 Closing Remarks

Fran Goldfarb



Virtual Happy Hour

