

AUCD/LEND FAMILY DISCIPLINE NETWORK 2004- 2021



WHAT IS THE LEND FAMILY DISCIPLINE NETWORK?

The Network consists of family members who have served as LEND faculty members for almost 30 years. Since 2004, Family Discipline Faculty have worked together to address issues unique to family inclusion in LENDs and beyond. Members represent all LEND programs across the country and bring their experience in academic and advisory capacities in numerous areas. They have also provided technical assistance through their AUCD 2007 publications: *“Promising Practices in Family Mentorship”*, *“LEND Family Discipline Competencies”*, *“Partnering with Professionals: Family-Centered Care from the Family Perspective”*, *Journal of Family Social Work (2010)* and *Fabric Not Fringe: Weaving Family Involvement throughout Training and Practice for Professionals and Advocate Working with Individuals with Disabilities and Special Health Care Needs, AUCD 2019* as well as numerous presentations at the annual AUCD and AMCHP Conferences.

LEND Family Discipline Network provides expert consultation from parents of children with disabilities and special healthcare needs for:

- **Training**
- **Curriculum, Product and Program Development**
- **Material Review**
- **Project Partnership**

THE LEND FAMILY DISCIPLINE NETWORK

Major Highlights:

2004

- Initial informal meeting of LEND family faculty at AUCD meeting
- Conducted a survey of all LEND programs about family involvement

2005



Family Discipline Meeting

- February 2005
- MCHB and AUCD Supported
- 50 attendees
- Workgroups:
Family Trainee
Competencies,
Family
Mentorship



2006

- Presentation for meeting of LEND Directors on the development of the Family Mentorship Guidebook
- Publication by AUCD of Family Discipline Network workgroup's two web-based products:
 - ***Family Discipline Competencies***
 - ***Promising Practices in Family Mentorship: A Guidebook for MCH-LEND Training Programs***
- Presentation by LEND Family Faculty members at AUCD Annual Conference on: **MCH LEND Family Mentorship Programs: What is it, why and how are individual programs unique, and what is next?**

2007

- AUCD network-wide national conference call on the activities of the LEND Family Discipline on : **Promising Practices in Family Mentorship and Family Discipline Competencies**
- Survey of LEND programs developed and conducted on: **The Inclusion of Family Discipline Trainees**
- AUCD Conference poster presentation on: **Family Trainees in LEND: Barriers, Successes and Strategies**

2008

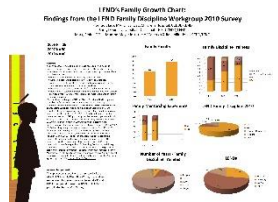
- Several LEND Family Discipline Network members joined the MCHB training priorities workgroup established in 2006 “ to promote family-centered/family-directed practices” . Together with representatives from other MCH training programs (and building upon such resources as the Family Mentorship Guidebook and Family Discipline Competencies) developed additional new training materials including: ***A Compendium of Family-centered, Family-directed Field Experiences, Guidelines for Establishing Family Advisory Boards, and Resources for Teaching Family-centered and Family-directed Practices*** published by the Maternal and Child Health Bureau (MCHB) (published 2008)
- Presentation at AUCD 2008 Annual Conference on: **Promoting Family-Centered/Family-Directed Practices that are Culturally and Linguistically Competent: Current Training Tools, Tips and Resources**

2009

- Crystal Pariseau presented with a Special Recognition during AUCD Awards Ceremony “in recognition of [her] vision, commitment, leadership, and enthusiasm in supporting our Network and promoting the Discipline of Family”
- Network members worked together on writing an article for the publication: ***Partnering with Professionals: Family Centered Care from the Family Perspective,*** [iii] published in the March-April 2010 *Journal of Family Social Work*, that provides insight from parent professionals who work in clinical settings and as faculty, to the ongoing challenge of actualizing the promise of family centered care

2010

- Survey developed and conducted to measure the character, diversity, and growth of the Family Discipline within LEND programs; and findings presented as a poster at AUCD Annual Conference: ***LENDs Family Growth Chart***
- Compilation of a resource directory of LEND family faculty’s areas of experience/expertise for distribution among and beyond LEND programs
- Materials developed by the Family Discipline Network were incorporated into a new public website: ***Guide to Developing Training Curriculum on Families, Disability, and Culture for MCH Trainees and Professionals***
- ***The Family Discipline in LENDs***, an article in *AMCHP Pulse Newsletter* (July, 2010)



2011

- Family Discipline Network’s poster: ***LENDs Family Growth Chart*** presented at AMCHP Annual Conference
- Development and dissemination of LEND Family Discipline Network Consultation brochure

- Family Discipline Network's poster: ***The UCEDD Family: Promoting and Supporting the Involvement of Families as Faculty, Staff and Advisors Beyond LEND Programs*** presented at the AUCD Annual Conference and Meeting
- Presented a poster on: Development of Family Faculty AUCD SharePoint site
- Subcommittee work on reporting about the impact of family involvement in LEND programs on former trainees representing all MCH disciplines

2012

- Concurrent session presentation: **The Family Clinic: Onsite Mentoring to Enhance Family Involvement in LEND and Other MCHB or UCEDD Training Programs** at the AUCD 2012 Annual Conference and Meeting.
- The LEND Family Network developed a survey for all LEND trainees on the value of family participation in LEND programs. Nine LENDs participated in the survey pilot.
- Many of our members have also joined the AUCD Family Support Special Interest Group (SIG).

2013

- Based on the results of piloting the Family Involvement in LEND trainee's survey, it was revised and approved as a research project by the Children's Hospital Los Angeles IRB. The 2013 survey was endorsed by AUCD and the LEND Training Directors Council and 187 trainees from 24 LENDs responded to the survey.
- Family Discipline Network's poster: ***The LEND Family Involvement Survey: Findings and Implications from Year One*** presented at the AUCD Annual Conference and Meeting
- Roundtable presentation as requested by LEND Directors, for their meeting during AUCD 2013 Conference.
- An article sub-committee was established to consider potential future publications.
- Exploring collaborative initiatives with the AUCD's Council of Community Advocacy (COCA) since many of our members have been involved with this council since its early establishment.

2014

- ITAC SharePoint Page Training and resource sharing
- ***The LEND Family Involvement Assessment*** was conducted LEND Network-wide from March through July 2014 after receiving an additional endorsement from MCHB. Re-designed as a simple online questionnaire that asks for basic demographic information on the type of family involvement present in each LEND program and their perceived impact and importance of that involvement. **178 trainees participated representing 22 LENDS.**
- The LEND Family Discipline Network will use this information to provide the AUCD and MCHB networks and the LEND leadership with a national picture of the value trainees place on family participation in LEND programs. (It is our hope that the survey will be supported by all LENDs and administered yearly to all graduating trainees).

- Concurrent session presentation: ***The Importance, Impact and Implications of Family Discipline in Training*** at the AUCD 2014 Annual Conference and Meeting. Part of this presentation session will include information related to ***LEND Family Discipline Trainees: Where do they go from here?***
- Ongoing networking and support for LEND programs due to the increasing number of LEND programs with Family Discipline trainees (including siblings) and Self-Advocate Trainees as well as new family faculty and those seeking resources for individual LEND program projects and initiatives.
- **Policy Webinar** by AUCD for Family Discipline Network members

2015

- Began work on the Fabric Not Fringe White Paper
- ***The LEND Family Involvement Assessment***
- LEND Family was conducted LEND Network-wide from March through July 2015 after receiving an additional endorsement from MCHB. Re-designed as a simple online questionnaire that asks for basic demographic information on the type of family involvement present in each LEND program and their perceived impact and importance of that involvement. **194 trainees participated representing 23 LENDS.**
- **Family Discipline Recruitment Survey** was developed
- Presentation of Concurrent Session at AUCD – **How LEND/UCEDD Programs are Driving Change by Training and Supporting a New Generation of Family Advocates and Disability Leaders.** Based on results of the LEND Family Discipline Recruitment Survey, Presenters included: Lurene Cichon, Wanda Felty, Sheryl Feuer, Fran Goldfarb, Ziporrah Levi-Shakleford, Barbara Levitz, Rylin Rogers, Phyllis Shingle, and Mark Smith

2016

- **LEND Family Trainee Facebook Page** was established
- Presentation of Concurrent Session at AUCD - **Fabric Not Fringe: Weaving Family Involvement Strategies into LENDs and other Professional Disability Related Training Programs** Presenters included: Amy Carlsen, Sarah DeMaio, Fran Goldfarb, Barbara Levitz, Julieta P. Hernandez, Mark Smith
- Collaborating with Family Support SIG on the Family Support Training Curriculum
- ***The LEND Family Involvement Assessment*** was conducted LEND Network-wide from March through July 2016 after receiving an additional endorsement from MCHB. Re-designed as a simple online questionnaire that asks for basic demographic information on the type of family involvement present in each LEND program and their perceived impact and importance of that involvement. **237 trainees participated representing 26 LENDS.**

2017

- ***The LEND Family Involvement Assessment*** was conducted LEND Network-wide from March through July 2017 after receiving an additional endorsement from MCHB. Re-designed as a simple online questionnaire that asks for basic demographic information on the type of family involvement

- present in each LEND program and their perceived impact and importance of that involvement. **257 trainees participated representing 18 LENDS.**
- **Presentation at AUCD - Why and How to Engage Families as Presenters in Training for Health, Education, and Law Enforcement Community Partners.** Presenters are Fran Goldfarb, Barbara Levitz, Mitchell Levitz, Dori Ortman, Linda Russo, Mark Smith.
 - **Presentation at AUCD in collaboration with the Family Support SIG - Siblings of People with Disabilities: Building Awareness and Support through LEND** Presenters included: Katie Arnold Fran Goldfarb, Nathan Grant and Barbara Levitz.

2018

- **The LEND Family Involvement Assessment** was conducted LEND Network-wide from March through July 2018 after receiving an additional endorsement from MCHB. Re-designed as a simple online questionnaire that asks for basic demographic information on the type of family involvement present in each LEND program and their perceived impact and importance of that involvement. **246 trainees participated representing 26 LENDS.**
- **Presentation at AUCD- How LEND Training Develops Family Leaders: Advocating For Inclusion in Community Life** Presenters include: Stephanie Coleman, Fran Goldfarb, Barbara Levitz, Jonna Mulvaney, Dori Ortman , Linda Russo, and Mark Smith

2019

- **The LEND Family Involvement Assessment** was conducted LEND Network-wide from March through July 2019 after receiving an additional endorsement from MCHB. Re-designed as a simple online questionnaire that asks for basic demographic information on the type of family involvement present in each LEND program and their perceived impact and importance of that involvement. **206 trainees participated representing 14 LENDS.**
- **Established LEND Family Discipline Network Steering Committee –** Stephanie Coleman, Cristy James, Dori Ortman, Linda Russo
- **Presentation at AUCD (in collaboration with the PWD Workgroup. Life After LEND: Family and Self Advocacy Fellows Go from Lived Experience to Leaders to Agents for Change.** Concurrent Session Jack Brandt, Alicia Curran, Sarah DeMaio, Fran Goldfarb, Michael Hoenig, Dori Ortman, Mark Smith,
- **Poster at AUCD - A New Resource - Fabric Not Fringe: Weaving Family Involvement Strategies into Professional Disability-Related Training Programs-** presenters included: Sarah DeMaio, Wanda Felty, Fran Goldfarb, Julieta Hernandez, Dori Ortman, Linda Russo, and Mark Smith
- **Initiation of Life After LEND Project**
- **Publication of the Fabric Not Fringe White Paper**



2020

- **The LEND Family Involvement Assessment** was conducted LEND Network-wide from March through July 2020 after receiving an additional endorsement from MCHB. Re-designed as a simple online questionnaire that asks for basic demographic information on the type of family involvement present in each LEND program and their perceived impact and importance of that involvement. **257 trainees participated representing 27 LENDS.**
- **Poster at AUCD - Moving Towards the Horizon: Seeking to Create a Truly Diverse Cadre of LEND Family Discipline Fellows-** Workgroup included: Susan Adelman, Stephanie Coleman, Wanda Felty, Emma Fox, Fran Goldfarb, Jonna Mulvaney, Dori Ortman, Linda Russo, Mark Smith. Presenter Jonna Mulvaney
- **LEND Family Competencies** serve as a model for the PWD workgroup

2021

- **The LEND Family Involvement Assessment** was conducted LEND Network-wide from March through July 2021 after receiving an additional endorsement from MCHB. Re-designed as a simple online questionnaire that asks for basic demographic information on the type of family involvement present in each LEND program and their perceived impact and importance of that involvement. **348 trainees participated representing 31 LENDS.**
- Presented **Fabric Not Fringe Webinar Series** in May 2021. Presenters included: Stephanie Coleman, Wanda Felty, Fran Goldfarb, Julieta Hernandez, Dori Ortman and Mark Smith
- Updated **Family Mentorship Guide** published
- **LEND Family Discipline Network Virtual Summit** in September 2021. Organizers were Kristin Flott, Angela Miney, Jonna Mulvaney, Stephanie Coleman, Wanda Felty, Fran Goldfarb, Tim Markle, Dori Ortman, and Mark Smith. AUCD: Jackie Czyzia, Emma Fox and Maureen Johnson