

**The LEND Family Discipline Network Presents:**  
***Fabric not Fringe Webinar Series***

**Part 4: Family Members as Trainees  
and Participants in Program Planning,  
Implementation, and Evaluation**

*Tuesday, May 25, 2021  
4:00 pm ET - 5:00 pm ET*

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## Introduction

*Fran D. Goldfarb*

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## Family Members as Trainees

*Fran D. Goldfarb*

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## Q&A

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## Family Members as Participants in Program Planning, Implementation, and Evaluation

*Fran D. Goldfarb*

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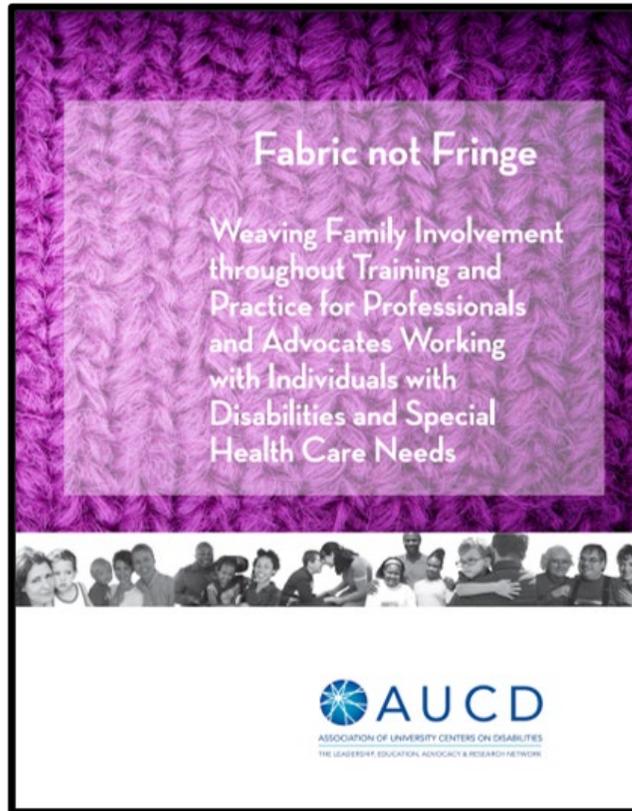
## Q&A

# INTRODUCTION

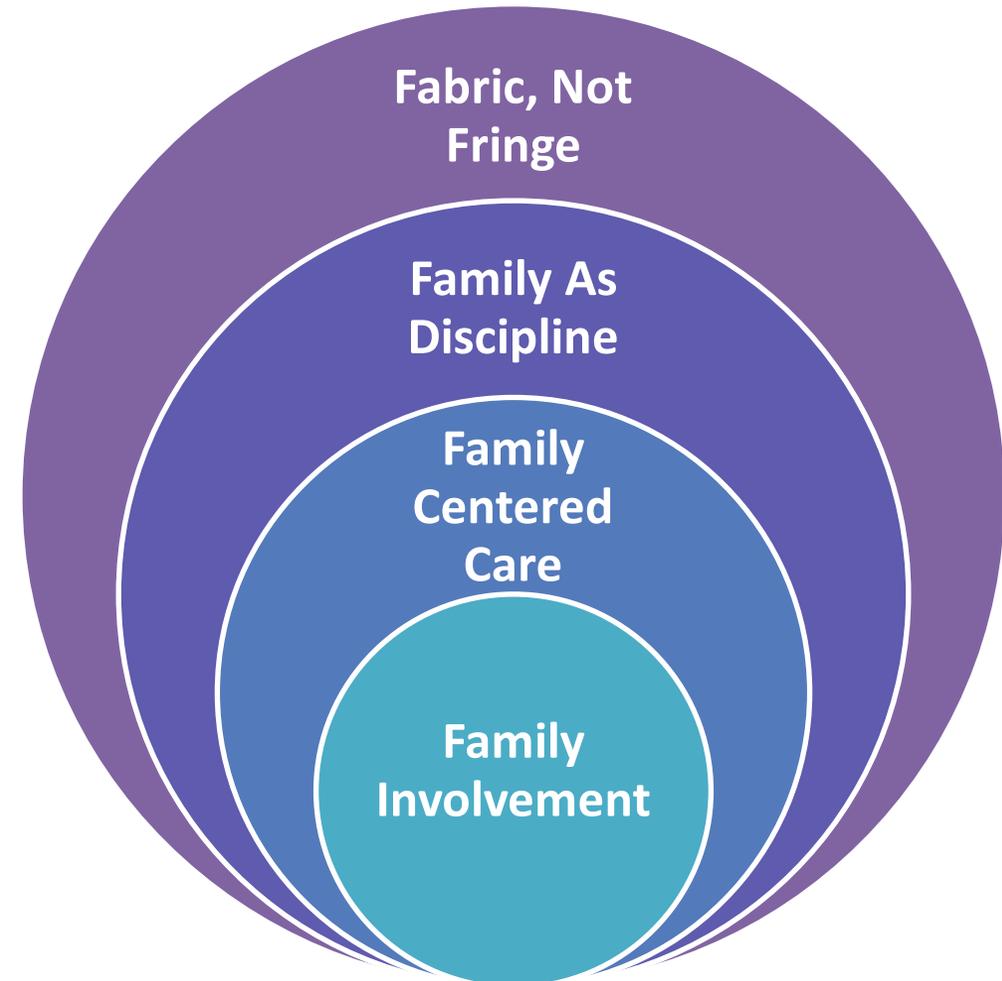
*Fran D. Goldfarb, MA, MCHES, CFPS  
Director, Community Education  
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# Family Involvement in LENDs



[Access the White Paper Here!](#)



# Family Involvement Survey

- 2012
- All graduating LEND fellows
- Importance and Impact of Family Involvement
- Identified 8 Types of Involvement



# Our White Paper Includes

**Definition**

**Best for  
Programs That...**

**Discussion of  
Need**

**Discussion of  
Benefit**

**Resources for  
Implementation**

**Strategies for  
Implementation**

**Addressing  
Barriers**

**Evaluating  
Success**

# The 8 Types of Involvement

- Family Members as Faculty or Staff
- Family Members as Supports in Clinical Settings
- Families as Mentors
- Families as Presenters and / or Panelists
- Family Members from the Community Serving on Advisory Boards, as Research Participants, or Consultants on Thesis Preparation
- Family-Focused Topics
- Families as Trainees
- Family Members Participating in Program Planning, Implementation, and Evaluation



- MCHB (Autism Cares Act)
- Advanced level interdisciplinary leadership training program
- Family participation is required
- Tend to think of
  - Family Faculty (1992)
  - Family Trainees (1995)
  - Mentors
- But indeed, there are other possible roles

## The Value of Family Involvement in All Professional Training:

The active participation of family isn't uniquely suited to LENDs. It has a fundamental role in all training.



DBP



LEAH



PPE



ETC.

**Fran D. Goldfarb** will discuss Families as Trainees and Family Members Participating in Program Planning, Implementation, and Evaluation



# Webinar Series Schedule

[Part 1 - Family Members as Mentors and Supports in Clinical Settings](#)

*Stephanie Coleman and Mark Smith*

[Part 3- Family-Focused Topics and Family Members as Board Members, Research Participants, and Consultants](#)

*Julieta P. Hernandez and Wanda P. Felty*

**NOW ARCHIVED!**

**NOW ARCHIVED!**

**ARCHIVED SOON!**

[Part 2- Family Members as Faculty, Staff, Presenters, and Panelists](#)

*Dori Ortman*

# **FAMILIES AS TRAINEES**

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No universal definition but, there are three common features:

- Relative of a person with a disability,
- Lived experience, and
- Advocacy/ Leadership experience.

Common Roles:

- Provide the family perspective,
- Represent family support as a discipline, and
- Serve as navigators to the systems serving people with disabilities.

# Best for Programs That...

Are interdisciplinary

Do not require  
university  
enrollment

Value learning with  
and from families

Have existing family  
faculty to guide and  
mentor trainees

Are open to  
differentiating their  
curriculum to  
support diverse  
learners

- Increased need for family members
  - in **leadership** positions
  - working in **direct support services**
  - as part of **interdisciplinary teams**
  - in **policy and systems change**
  - Family as systems change leadership

**There is need for family members to have access to the same leadership training available to other professionals in the disability field.**

# Discussion of Need, contd.

Other disciplines need to learn from and with family members to fulfill commitment to Family-Centered Care and parent-professional partnerships.

LEND Family Involvement Survey confirms **having family trainees in their program is important and impactful** (Goldfarb et al., 2013-2016). LENDs have been including trainees for more than 20 years and family is one of the core LEND disciplines required by MCHB.

# Discussion of Benefits

- LEND Family involvement survey on importance of having family participation (instituted 2012).
- Family Trainees
  - **90% of fellows** rated the inclusion of family trainees as important or very important and rated the impact as high or very high.

## Examples of the reported benefits include:

- the helpfulness of **hearing about family members views** and opinions,
- **increased awareness** of the family perspective,
- broadening their perception to **view families as peers**, and
- increased appreciation for the **value of parent-to-parent support**.

# Discussion of Benefits, contd.

## Benefits to Family Trainees:

- increased appreciation of **the challenges professionals face** in providing care and
  - strengthening the potential for **true partnership**.
- Often the family members are a little older and **more experienced with service systems** and provide a more realistic understanding how systems work.

# Strategies for Implementation

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Start with a **family faculty member**.

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Family members may have very full plates; some may not be able to commit to a long-term fellowship. **Short or medium terms** may be a way to get family members started.

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Start by doing an **asset map for health, financial and community resources**. Share this information with your department to see if they can help “activate” the resources.

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Recruitment can include parent professionals in community agencies, support group leaders, **Partners in Policymaking** graduates, and parents serving on disability-related advisory boards and boards of directors.

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Network with **minority-serving support organizations** to increase diversity. Recruit undocumented families (be aware of language barriers) through connections in the community, specifically through partnerships with community-based organizations and agencies.

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Take advantage of **existing materials** such as the CA-LEND Pathways to LEND (pre-teaching for LEND family support trainees) and the Parent Portfolio, a tool for gathering relevant family life experiences to develop a family discipline resume.

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Provide **stipends** for family trainees. Most LENDs provide stipends that are on par with stipends for other disciplines.

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If family trainees are working as parent professionals, **document how LEND participation is of benefit to the agency** – often this will encourage the agency to provide release time and/ or reduced work thus allowing the LEND trainee to more successfully integrate LEND into their schedule.

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Family trainees may need **additional support/mentoring** from their discipline supervisor, but most programs do not need to modify their curriculum.

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Consider having a **longer training period**, e.g. two years instead of the standard one year LEND program.

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Use the **ITAC toolbox** for additional implementation strategies: [www.aucd.org/itac](http://www.aucd.org/itac)

# Addressing Barriers

To address the issue of faculty who don't understand the value of having family trainees, **talk with programs that currently include family members** as trainees.

If you find that family trainees may be intimidated by trainees from "professional" disciplines, **provide emotional and/or academic support** needed to the family trainees (as needed) and carve out specific opportunities for their voices to be heard.

Since family trainees may not have the same academic preparation as other disciplines, **consider pre-training** in areas family trainees may have less experience in (e.g. literature review). See: Pathways to LEND for a model.

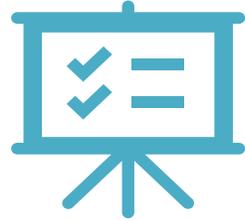
Because family members may have very full plates, **consider opportunities for shorter term participation** (e.g. short term or medium-term trainees) or a **longer training term** (e.g. two years instead of one).

Family trainees may have a crisis or just conflicting demands during their training, so **consider pre-planning for possible barriers to participation** and identify solutions/strategies like asynchronous learning modules or distance learning.

# Evaluating Success



Incorporating family members as trainees may be a **multi-step process**, so evaluation should include both readiness and then success.



Evaluating the success of your trainees **can include standard assessments used for all trainees.**



Identification of areas of challenge for family trainees (e.g. literature reviews or other more academic tasks); **evaluate the success of family trainee-specific strategies.**



Evaluation of **trainee recruitment and applicants.** Inclusion of family members may require different recruitment strategies than used for other disciplines.

# Resources for Implementation

NDD Curriculum Resources: A repository for curricular materials currently being used within the LEND network. Email Emma Fox for access ([efox@aucd.org](mailto:efox@aucd.org))

LEND Family Competencies: <https://tinyurl.com/LENDFamilyCompetencies>

Strengthening Family Involvement in LEND Training Programs Webinar:  
[https://www.aucd.org/template/event.cfm?event\\_id=7986](https://www.aucd.org/template/event.cfm?event_id=7986)

Institute for Patient and Family Centered Care Partnering with Patients and Families to Design a Patient and Family-Centered Health Care System: <http://www.ipfcc.org/resources/PartneringwithPatientsandFamilies.pdf>

Pathways to LEND/Parent Portfolio available from Fran Goldfarb at CA LEND: email [fgoldfarb@chla.usc.edu](mailto:fgoldfarb@chla.usc.edu)

The ITAC Training Toolbox: [www.aucd.org/itac](http://www.aucd.org/itac)



# Q&A- FAMILIES AS TRAINEES

Submit questions via the chat box, raise your hand in the participants box, or unmute yourself to ask a question

# **FAMILY MEMBERS PARTICIPATING IN PROGRAM PLANNING, IMPLEMENTATION, AND EVALUATION**

*Fran D. Goldfarb, MA, MCHES, CFPS  
Director, Community Education  
USC UCEDD CHLA*

This type of involvement includes family input at all stages of program design, including:

- serving as members of the planning team,
- designing models for implementation, and/or
- participating in program evaluation (and subsequent revision).

“Front end” participation

Family participants may be:

- members of the program faculty,
- the advisory board,
- past trainees, and/or
- community members.

# Best for Programs That

Value family input at all levels

Have access to family members who are familiar with the program

Are writing initial or renewal applications

May not have family members as faculty or staff

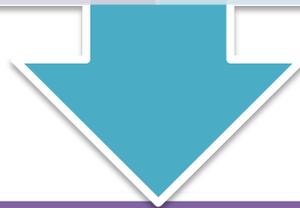
Are considering adding family members as faculty/staff and/or trainees

Are interested in evaluating the family centeredness of their program

Family-Centeredness is

a core value of all MCHB training programs, and

is considered a fundamental competency.



Programs that seek to develop Family-Centered programs logically must demonstrate those values.

# Discussion of Need, contd.

- Family-Centeredness, by definition, is a **partnership and should exist at all levels:**
  - systems,
  - programs, and
  - individuals.
- Family members participating in program planning, implementation, and evaluation occurs at the programmatic level.
- Family input is necessary to a Family-Centered problem.
- Family-Centered Care has been a required component for all MCH trainees with an expectation that all HRSA programs demonstrate 100% Family-Centered Care (since 2008)

# Discussion of Benefits

Allows for the family voice to be fully integrated. This increases the likelihood of program success.

It also models authentic family involvement to other faculty/staff and to trainees.

Family participation increases the likelihood that programs are mindful of cultural considerations.

Family involvement can transform your capacity for Family Centered Care (Family Engagement in Title V (MCHB)).

Fast Facts on Family Participation (Colorado Department of Public Health and Environment)

- improved State and community needs assessment process,
- increased Number of effective family advisers within community/programs and
- reduced Perpetuation of narrow scope of work in grant proposals.

# Strategies for Implementation

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Provide **training and support** for family members to help prepare family members for meeting and debrief after the meeting.

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Involve family discipline **graduates**.

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Work with **existing family organizations**, e.g. Family Voices, Family Resource Centers.

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Investigate **Partners in Policymaking** in your state. If your state doesn't have one, consider starting one.

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Provide **ladders of involvement**: helping families develop skills to participate in program planning, implementation, and evaluation.

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Offer **childcare**.

# Strategies for Implementation, contd.

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Provide **translated materials and interpretation** at meetings, if needed.

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Involve family members in **reviewing publications**

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Involve family members and Self-Advocates in **reviewing training applications and interviewing trainees**

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Ask mentor parents to review their experience and the trainee they mentored. **Compile the data** for the benefit of future trainees

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Include family members in **site visits**

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Other ideas for implementation are available in the Family-Centered Care Section of the **ITAC toolbox** for additional implementation strategies:  
[www.aucd.org/itac](http://www.aucd.org/itac).

# Addressing Barriers

Attitudinal barriers (as demonstrated by a lack of understanding or resistance by faculty and/or community) can be addressed by talking with programs that currently include family members to demonstrate the potential for success.

In order to recruit high quality family leaders, a clear understanding of their role and the importance of their involvement needs to be articulated and communicated.

# Addressing Barriers, contd.

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To avoid tokenism, families need training and support if they are to actively participate. This may require additional faculty/staff time.

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Families represent their community; programs should not only include those who are “easy” to include. This may result in cultural and linguistic barriers to inclusion. Be prepared to engage in cultural and linguistic competency training and require translation of materials and interpretation at meetings as needed.

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Involving families can result in logistical barriers. Programs need to be prepared to be flexible in meeting times, locations and modalities. Consider options for remote or asynchronous participation.

# Evaluating Success

Family Voices Family-Centered Care Self-Assessment Tool Provider Tool:  
[http://www.familyvoices.org/admin/miscdocs/files/fcca\\_ProviderTool.pdf](http://www.familyvoices.org/admin/miscdocs/files/fcca_ProviderTool.pdf)

Family Tool: [http://www.familyvoices.org/admin/work\\_family\\_centered/files/fcca\\_FamilyTool.pdf](http://www.familyvoices.org/admin/work_family_centered/files/fcca_FamilyTool.pdf)

User's Guide:  
[http://www.familyvoices.org/admin/work\\_family\\_centered/files/fcca\\_UsersGuide.pdf](http://www.familyvoices.org/admin/work_family_centered/files/fcca_UsersGuide.pdf)

Institute for Family-Centered Care – Self Assessment Tools:  
<http://www.ipfcc.org/resources/assessment.html>

Institute for Patient and Family-Centered Care Partnering with Patients and Families to Design a Patient and Family-Centered Health Care System:  
<http://www.ipfcc.org/resources/PartneringwithPatientsandFamilies.pdf>

# Resources for Implementation

- Family Involvement, the Division of MCH Workforce Development  
<https://mchb.hrsa.gov/training/hi-family-involvement.asp>
- MCH Public Health Leadership Institute Adaptive Leadership and Increasing Meaningful Partnerships between Families and MCH Partnerships  
[https://mchphli.org/?page=try\\_a\\_module](https://mchphli.org/?page=try_a_module)
- MCH Training Guidelines For Establishing Family Advisory Boards.  
<http://media.mchtraining.net/training/documents/hi-fi-Guide-for-Establishing-Family-Advisory-Councils.pdf>
- AMCHP Levels of Family Engagement in Title V MCH and CYSHCN Programs  
<http://www.amchp.org/programsandtopics/familyengagement/SiteAssets/Pages/default/Family%20Engagement%20Levels%20of%20Family%20Engagement.pdf>
- Fast Facts on Family Participation (Colorado Department of Public Health and Environment)  
<http://www.chd.dphe.state.co.us/Resources/cms/ps/hcp/Resources/Fast%20Fact%20Sheet%20-%20Revised%20Family%20Participation%20for%20MCH%20audience.pdf>
- Family Engagement in Title V (MCHB)  
<http://www.amchp.org/AboutTitleV/Resources/Documents/Family%20Engagement%20in%20TitleV.pdf>



# **Q&A- FAMILY MEMBERS PARTICIPATING IN PROGRAM PLANNING, IMPLEMENTATION, AND EVALUATION**

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# THANK YOU!

This webinar will be archived. Please take a few moments to complete the evaluation survey.

## Presenter Contact Info:

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Scan me with your  
smart phone to  
complete the  
evaluation!