

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

**Part 1: Family Members as Mentors
and Supports in Clinical Settings**

*Monday, May 10, 2021
12:30 pm ET - 1:30 pm ET*

Introduction

Fran D. Goldfarb

Family Members as Mentors

Stephanie Coleman

Q&A

Family Members as Supports in Clinical Settings

Mark A. Smith

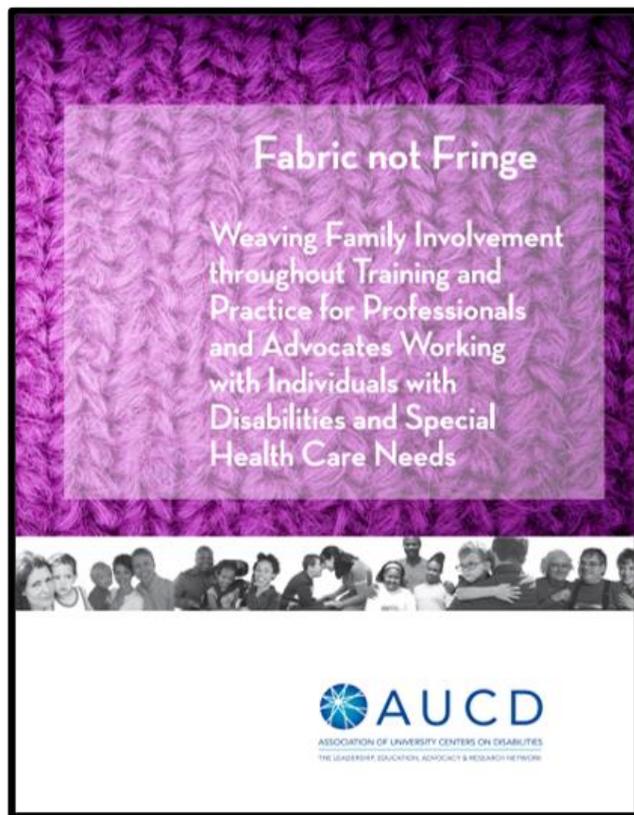
Q&A

INTRODUCTION

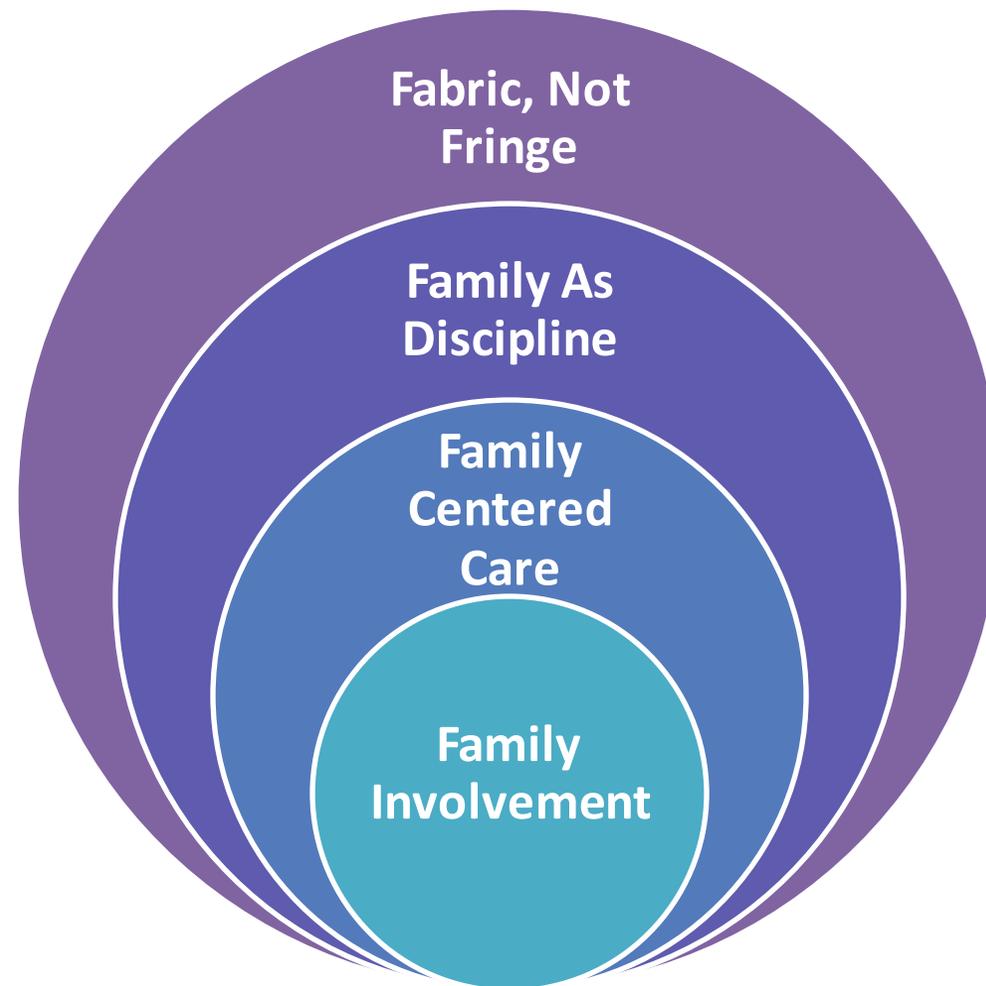
*Fran D. Goldfarb, MA, MCHES, CFPS
Director, Community Education
USC UCEDD CHLA*



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.

In This Session

Stephanie Coleman will discuss family members as mentors; highlighting the importance of understanding the family experience



Mark A. Smith will discuss how Family Support functions in a clinical role or setting



Webinar Series Schedule

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

Dori Ortman

[Part 4- Family Members as Trainees and Participants in Program Planning, Implementation, and Evaluation](#)

Fran Goldfarb

Monday, May 24th, 2021

1:00 pm Eastern

Wednesday, May 19th, 2021

3:00 pm Eastern

Tuesday, May 25th, 2021

4:00 pm Eastern

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

Wanda Felty and Julieta Hernandez

FAMILY MENTORS: LEARNING FROM THE LENS OF LIVED EXPERIENCE

Stephanie Coleman

Family Discipline Mentor

Kansas LEND, University of Kansas Medical Center

Definition of Family Mentors

“Families of children with special health care needs are matched with trainees in the institution’s training program. By sharing their experiences and perspectives with the trainees, families help them develop important leadership competencies, such as family-centered care skills. Trainees learn the positive and negative experiences families have encountered within health care systems. **In this capacity, the families are the teachers, and the trainees are their students.**”

Fabric not Fringe Whitepaper, April 2019

Kansas Family Mentors

- Kansas LEND – state line
- Families across Kansas who have a child with a disability
- Two-parent households, single parents, foster parents, generational households
- Culturally Diverse
- Rural and frontier locations

Need for Family Mentors

Family-
Professional
Partnerships

Cultural
perspectives

Provide self-
reflections and
perspective

Working with
Communities
and Systems

Communication

Increase
medical care
professional
training

Hearing from the
experts

Trainees get a
glimpse into the
daily life of
families

Family-centered
care skills

Need – Family Perspective

- “I feel it's important for a person who will be working in the field to **understand what the families go through daily.**”
- “We wanted to give back to our community by offering an interested student to learn about our family, including the **joys and challenges** of being a family with a special needs child.”
- “I want professionals to have experience with families so they can learn **how to serve families' needs.**”
- “I feel it's important to **experience daily life** of special needs families in order to better help them.”
- “I think it is important to **understand what families really go through** in raising a child with special needs.”

Impact of COVID-19

- Innovative ways to connect
- Reaching new communities of families
- Exciting opportunities to observe and discuss parts of family life
- In-person activities AND Video-conferencing (Zoom/Teams)
- Monthly meetings
- Interview Sections

Activities

- Morning, Afternoon or Evening routines
- Mealtimes
- Medicine routines
- Doctor or therapy appointments
- Individualized Education Program (IEP) Meetings
- Community activities
- Sports



Time - schedules



Technology



Communication

Benefits and Successes

“I had the opportunity to build a bond with my family, learn more about how disability impacts their lives, and **along the way provide resources that could be helpful to them.** I am forever grateful for this experience, and I will take what I’ve learned into my future practice as an occupational therapist.”

“I love to hear **how different their lives are**, living in rural Kansas and not being as affected as the bigger cities by the pandemic.”

“I love the fact that whenever she has a question, and I can't answer or provide resources right there, **I feel like it is my mission to get her questions answered by tapping into all the resources I received through LEND.**”

Benefits and Successes, contd

“... we were all introduced to the **experts of family-centered care;** the parents of children with disabilities.”

“I think the greatest change in my perception and understanding of the experience of a family experiencing disability started with the realization that **there’s much more to disability than simply loving or caring for someone diagnosed with one.** Disability exists as a multifaceted, complex experience for each individual and their families. As such, we cannot treat disability as a monolithic experience... each disabled persons’ lived experience is unique to them and them only.”

“If someone is asking for a certain accommodation or reacts differently to a situation, **they don’t owe anyone an explanation.** Instead, we need to adapt, like so many of these children and families do, and find the best way to support them.”



Q&A- FAMILY MEMBERS AS MENTORS

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

FAMILY MEMBERS AS SUPPORTS IN CLINICAL SETTINGS

Mark A. Smith, MS

Assistant Professor, LEND Family Faculty

Munroe-Meyer Institute LEND/UCEDD, University of Nebraska Medical Center

The Family Support Movement

The peer-to-peer model

- The role of families as emotional and informational support to other families
- The role of persons with disabilities as peer support
- The importance of training with both types of activities

The Medical Home Model

Key components:

- Comprehensive
- Patient-centered
- Accessible
- High quality including quality improvement, evidence-based, and shared decision-making
- Coordinated care

Definition and Discussion of Need

- Families of children with special healthcare needs and disabilities
 - Medical Home as best practice *versus* requisite practice
 - As medical complexity increases...
- Transitioning to the Medical Home model
 - How do Medical Home practices “map” onto traditional Medical Model practices as pediatric practices change?
 - Personnel roles
 - Practice activities
 - Role of insurance/funding

The needs of families in navigating healthcare services:

As complexity increases, who serves as the most credible resource?

- What families tell us:
 - Navigating systems is a stressful process, **particularly during transitions**
 - Families often report that **peers with lived, similar experience** are perceived as more credible from the outset
 - Maintaining scheduled appointments with Medical and Allied Health specialists can be **difficult**

- What medical providers tell us:
 - Merely connecting a parent with a peer mentor **does not serve the purposes** of the medical service
 - That they **do not perceive other parents as potential care coordinators** or professionals at the same level as others
 - They perceive issues - for example collaboration with specialists, ensuring referrals to community services are followed up on, information is shared, follow-up appointments are met – but **don't always have the time or resources to address them**

Family Members as Clinical Coordinators

- Plenty of titles to choose from: Care Coordination, Public Health Workers, Parent Resource Coordinators, Peer Mentors, etc.

The Main Point:

There are advantages to employing people with the lived experience of caring for a child with special needs in this *care coordination* role

What might this include?

- Navigators
- Coordinators
- Support brokers
- General information resources
- Advocates
- Obtaining benefits or services in the community
- Transition support

What might this not include?

- Providing medical or allied health treatment or advice
- Assuming the role of other case managers or services coordinators involved

- This is best for medical and allied health practices that:
 - serve the medical needs of individuals with disabilities or chronic healthcare needs that are **complex and require multiple service providers**
 - **lack identified staff** in the role of professional care coordinators
 - may have access to a cadre of parents or caregivers who are **trained or are willing to be trained** in care coordination principles and medical and community resources
 - have **funding** to compensate parent resource coordinators

Lessons Learned in Implementation, contd

Training and communication are critical.

Ensuring care coordinators have the skills necessary to work with families in clinical venues is a necessity

Remember that you are “selling” a service that providers might not be aware of the need for

Initial resources - funds - are needed to accomplish both staff training and outreach to medical providers; grant funding is one example.

Careful planning is critical as well in order to avoid unintended outcomes.

Sustainability funding to continue services if an initial funding resource is temporary is another issue that should be addressed.

Implementing methods to evaluate progress in your initial efforts is an important step.

Are you accomplishing the intended ends? This is important for sustainability and program expansion.

Lessons Learned in Implementation, contd

Partnerships with other entities who are experts in program planning, implementation, training, assessment, etc. can go a long way in **ensuring success**

UCEDDs, LENDs, Early Intervention, Title V, state subdivisions of the Academy of Pediatrics, Parent Training Centers, etc.

Tip: start collecting data from the start!



Nebraska examples (recognizing other state systems have traveled different paths...)

The Family Care Enhancement Project, University of Nebraska Medical Center Munroe-Meyer Institute Sarah.Swanson@unmc.edu

The Hali Project, Brad Thompson <https://www.thehaliproject.org/>

The Rhode Island Parent Information Network, Practice Enhancement Project
<http://www.ripin.org/>

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

The ITAC toolbox contains information on additional implementation strategies:
www.aucd.org/itac



Q&A- FAMILY MEMBERS AS SUPPORTS IN CLINICAL SETTINGS

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

THANK YOU!

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

Presenter Contact Info:

- Fran Goldfarb, fgoldfarb@chla.usc.edu
- Stephanie Coleman, scoleman3@kumc.edu
- Mark Smith, msmitha@unmc.edu



Scan me with your
smart phone to
complete the
evaluation!