

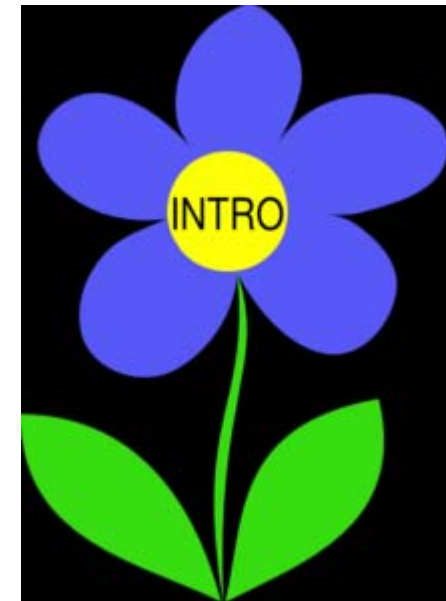


Strengthening Family Involvement in LEND Training Programs

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Family Support in the CA-LEND Program

- Family Support Trainees since 1995
- Family Faculty since 1997
- Target - 2 Long Term Trainees a year
- Family Support Trainees participate in all LEND activities and are expected to do the same work.



Innovations and Resources

Eligibility



Parent Portfolio
Qualifications/
Equivalent
Experience

Orientation



Information
Meeting
Pathways to LEND
Flare Plan

Support During
Training



2-year Program
Extra supervision
Curated Leadership
Projects

Professional role of
LEND or university
faculty and staff

Interdisciplinary
Team Members in
Clinical Settings

Family Mentors

Guest Presenters or
Panelists

Roles for Families in CA-LEND

LEND Program
Advisors

Training curricula

LEND Trainees
From the Family
Discipline

Participating in
Program Planning,
Implementation,
and Evaluation

Family Members in Other MCHB Training Programs

Faculty in Developmental Behavioral
Pediatrics Program



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Strengthening Family Involvement in LEND Training Programs

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WIHD 's LEND Training & UCEDD



- Families employed as faculty and staff since 1990
- Families in key leadership roles
- LEND Family Discipline trainees since 2001 and follow same program as other trainees. Typically 2-4 long-term trainees each year (parents & siblings)
- **Family trainee involvement post-LEND:** guest presenters, mentor families, advisory committee members, assist in recruitment, assume faculty/staff and community positions, and serve on local and state councils



The FAMILY PARTNERSHIPS Curriculum Module

- ❑ **Family Faculty:** Curriculum Development, Coordination, Instruction and Evaluation
- ❑ **Family Topics and Assignments (pre-class & long-term):**
 - Family-Centered Practices & Family/Professional Collaboration
 - Family Quality of Life and Advocacy, Family Support and Family Involvement in Program Planning, Implementation and Evaluation
 - Ethics-Partnerships in Healthcare Decision-making

Key Assignments: *Family-Focused Disability Organization Interview and Family Mentorship*



Selected Resources and Strategies

- Using videos and articles by families for trainees to understand the uniqueness of family experiences and personal perceptions of disability
- Family Trainees individual presentations on *Family Quality of Life & Advocacy*
- Parents invited as guest panelists (some session topics & issues pre-requested by trainees)
- Trainees review a “family-friendly” self-assessment tool and share strategies to increase family involvement in individual & organizational practices and advocacy



Selected Resources and Strategies

- Siblings invited as guest panelists (session may also include LEND trainees from other disciplines who are siblings)
- A network of “Mentor Families” provide home visits and community outings
- Transition module: UCEDD parent staff participate in a mock person-centered transition planning meeting and self-advocates dialogue with groups of trainees
- Policy & Advocacy module: *Community Advocacy Leaders Interviews* include “**Family Leaders**”



Promoting MCHB Values in Training Other Health Professionals

Foundations of Clinical Medicine 1: Caring for Patients with Disabilities

- Co-coordinated by LEND Family Faculty
- Groups of first year medical students meet with families. Presenters are *either* parents of individuals with I/DD or individuals with disabilities and their parents and/or siblings

Developmental Medicine Workshops for Family Medicine Residents

- Co-presented by LEND Director with Family and Self-Advocacy Faculty





Strengthening Family Involvement in LEND Training Programs

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Family Involvement in the UAB – LEND Program

- Family Faculty since 2009
- Family Trainees since 2015
*still learning
- Family Trainees participate in all LEND training activities, but is designed to have greater flexibility
- 1 Long-term Trainee a year



Family Trainee additional curriculum



Advocacy –

- visit local state representatives to educate them about our programs
- attend AUCD Disability Policy Seminar and educate our state representatives about our programs in D.C.

Family Mentors -



Family perspective in areas within the State of Alabama

- UCEDD - Consumer Coordinator
 - Consumer Advisory Council
- Alabama Council on Developmental Disability
 - Council Member
- Alabama Disability Advocacy Program
 - Protection and Advocacy for Persons with Developmental Disabilities, PADD Council



Family perspective in areas within the UAB System

- Alabama Maternal & Child Health Partnership
- UAB Continuing Medical Education Committee
- Children's of Alabama
 - Pressure Injury Safety Team
 - Family-Centered Rounds Task Force Committee



Family perspective in areas within UAB Maternal & Child Health

Pediatric Pulmonary Center - Family Faculty/Leader





Strengthening Family Involvement in LEND Training Programs

Phyllis Shingle

NM LEND/PPC Family Faculty

University of New Mexico

Center for Development & Disability

Family Involvement

- Family Centered Care Seminar
- Family and Community as Faculty (FACF)
 - 23-26 families and self-advocates
- Family Discipline Trainees
 - 2-3 family trainees each semester
- Family Directed Activity
- Guest panelists and/or presenters
 - Youth self-advocates
 - Sibling
- Maternal Child Health Advisory Committee
- Review documents/procedures as requested

Family and Community as Faculty (FACF)

- Trainees matched with FACF since 2005
- All trainees matched with a family or self-advocate
- Trainees spend 20 hours over 2 semesters with FACF
 - Home visits, activities in community, appointments, etc.
- Invited to apply as a family trainee
- Recruit from advocacy groups, councils and support groups
- Pediatric Residents one-time home visit

Supporting FACF members

- Families & self-advocates attend summer workshop
 - Opportunity for training, support and networking
- Meet-and-Greet with trainees
 - Helps with 1st visit awkwardness
- Family as Faculty Coordinator
 - Assists with recruitment & matches
 - Checks in with families/self-advocates
- Families participate in annual MCHB Advisory Committee Meeting
- Stipends
- Feedback evaluations

Family Trainees

- Family Faculty as staff since 2005
- Family Trainees since 2007
- Family Trainees application process
 - No degree or graduate program required
 - Online application
 - Submit essay and references
 - Transcripts and resume optional
 - Paper application available
- Aim for 2 Family Trainees each semester
 - Support each other
- Same stipends as other trainees

Family Trainees Participation

- Same activities as other trainees
 - Accommodations as needed
- Matched with another family or self-advocate
 - Initially family trainees were not matched with FACH
 - Different experience other than their own
- Mentoring with Family Faculty
 - Additional time may be needed
 - Debriefing and processing

Family Directed Activity

- 4-5 small teams of trainees
- 4-5 family members
 - 1 family member/team
- Interview
- Identify concerns/needs
- Research
 - Team members divide up topics
- Share information with family
- Debrief and Feedback

Collaboration with MCH Programs

- MCH Advisory Committee and Collaborative
- Partnership with UNM Pediatric Pulmonary Center (PPC)
 - PPC trainees join for selected seminars
 - PPC Faculty Liaison with LEND
 - Shared Family Faculty
 - Family Trainee
- NM Title V Children's Medical Services (CMS)
 - Seminar Presenters
- NM Family Voices – Parents Reaching Out (PRO)

Resources for LEND Family Disciplines

- LEND Family Discipline Network
 - National Network of LEND Family Discipline Directors (and other interested folks)
 - Work on National Projects
 - Provide Mentorship to other LEND Family Faculty
 - For more information contact Fran Goldfarb fgoldfarb@chla.usc.edu or Sarah DeMaio sdemaio@aucd.org

Resources for LEND Family Disciplines

- LEND Family Discipline Products
 - LEND Family Discipline Competencies (2006)
<http://www.aucd.org/template/page.cfm?id=119>
 - Promising Practices in Family Mentorship (2006)
 - <http://www.aucd.org/template/page.cfm?id=119>
- ITAC Toolbox – Family Centered Care
 - <http://www.aucd.org/template/page.cfm?id=119>



QUESTIONS?