Training, Supporting, and Engaging Family Members as Participants in LEND Programs

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Why is this a Priority?

• “The family’s experience is an irreplaceable body of knowledge and represents qualifications to improve service... beyond what any degree or certification might provide.”¹

• Participation in training is mutually beneficial for family and professional trainees, but the supports needed to access the full curriculum may differ because of life circumstances

• At least 10% of LEND and DBP programs identified “support and inclusion of family members in training” as a top technical assistance need

Focused Assistance to Support Training (FAST) Projects

• Funded through a cooperative agreement between AUCD and HRSA’s Maternal and Child Health Bureau

• Eligible programs submitted proposals for brief, low-cost (up to $7,000) projects to build capacity in one priority area

• Selected programs based on:
  • Alignment of needs, goals, objectives, and activities
  • Potential program and network impact
  • Measurement and sustainability

• Receive ongoing technical assistance from AUCD, MCHB, and other programs (e.g. peer-to-peer conference calls)

• Required to submit multiple progress reports and disseminate findings, products, etc.
Session Overview

• Explore the traditional roles of family members within LEND

• Identify the primary issues family members face as it relates to their participation in interdisciplinary training

• Highlight two FAST projects that addressed these issues in innovative ways

• Discuss lessons learned, promising practices, and opportunities to advance the broader network
Family Discipline Defined

• “… that body of knowledge about the child / family member with a disability, that is inherent to the family, acquired by life experience and affected by culture and community.”

• Family Discipline Faculty (or Consultant)
  • Mandated by MCHB since 2005; same year they adopted a revised definition of family-centered care
  • Family Discipline Competencies for Trainees
  • Guidebook for Family Mentorship

2 Center for Learning and Leadership, 2006
Roles of Family Members

• Family Discipline Trainees
  • Training in the discipline of family, guided by the “competencies”
  • May be enrolled in graduate or undergraduate coursework
  • Long-term or medium-term trainees

• Family Mentors
  • Family member mentoring trainees
  • Receive a stipend for service (or voluntary)
Roles of Family Members (cont.)

- Guest Speakers or Panelists
  - Used at a variety of different LEND events
  - Parents, grandparents, siblings, and foster parents

- LEND Administrative Staff

What other roles do family members have in your LEND programs?
Problems and Issues Families Face

• LEND Family Fellows face many problems and issues when they enter the program:
  • Issues related to their families
  • Issues related to self
  • Issues related to their environment
Issues Related to Families

• Time
  • Securing enough time away from the day-to-day management of being the parent or family member of someone with a disability
  • Care coordination, health care, and educational needs

• Child Care
  • Locating appropriate child care
  • Coordinating enough care to meet the variety of program requirements (including travel and day/evening commutes)

• Child Health
  • Chronic or unexpected events
Issues Related to Self

• Cultural Barriers
  • Concern that cultural and familial traditions will be incongruous with the medical model
  • A family’s “culture” of disability will conflict with beliefs held by others
  • Concerns about “fitting in” with academic culture

• Language Barriers
  • Difficulty participating in discussions and working collaboratively

• Education
  • Lack of exposure to college and/or graduate coursework

• Transportation
Issues Related to Environment

• Lack of formal training in research and clinical practice
  • The requirements for these components as described in program materials can be particularly daunting

• Intimidation
  • Lack of experience with higher education
  • Negative experiences in a hospital and/or with physicians
Va-LEND
Planting the Seeds for Increasing Family Involvement

• Issues We Sought to Address

  • An “acceptable” level of family member participation in Va-LEND activities is not enough

  • To recruit more family members into current activities, we need to know more about the barriers affecting participation

  • Future supports offered to family members to increase their participation must be those that family members identify as needed
Goals and Objectives

• Goal 1: Former and current Family Mentors will identify supports that they consider needed to increase their participation in Va-LEND

• On-line survey field to be tested, implemented and analyzed by project “Seed Team”
• Results of survey to be used as basis for discussion at May, 2015 “Day of Gardening” meeting
• Findings from the meeting to be used to guide faculty in identifying support resources
Goals (cont.)

• Goal 2: Recruitment efforts will result in an increase of number of family member trainee applicants, at least 1 of whom is a Family Mentor for 2015-16 cohort
  • Develop recruitment plan
  • Implement plan
  • Offer individualized support options

• Goal 3: Va-LEND faculty and staff will identify activities and opportunities for family members throughout the program, including becoming Family Mentors and faculty
  • On-going dialogue at faculty meetings March – May
  • Collect data on family member participation over time to look at trends of support, experience and training needed to assume LEND faculty positions
Activities and Accomplishments

• Goal 1 – Identification of Needed Supports
  • Needs survey
  • On May 16th, we…
    • Designed the garden
    • Prepared the soil
    • Planted the seeds
    • Pulled weeds
    • Fertilized the plants
    • Harvested what we had sown…
  • And realized that we were completely wrong about how we were looking at supports that families need to participate in Va-LEND!
Activities and Accomplishments (cont.)

• Goal 2 – Recruitment
  • 4 applications received from family members for Long Term Trainee 2015-2016 cohort – all had attended the May 16 meeting – and all were accepted
  • Money that was remaining in the budget used to support a family member as a Medium Term Trainee
  • Field testing a potential new category in Va-LEND of medium term trainees
  • Funding request in process to use carry over funding to support a recruitment session in Spring 2016 targeting family members and self-advocates
Activities and Accomplishments (cont.)

• Goal 3 – Additional roles for family members within Va-LEND
  • Addition of family member on interdisciplinary teams in Teamwork Class
  • Role for family discipline trainees within Interdisciplinary Clinics
  • Activity continues…
Challenges

• Most important things that we learned are our greatest challenges:

  • The BARRIERS To family member participation cannot be looked as individual problems

  • Having a child with a disability increased the UNPREDICTABILITY factor – something unplanned can happen at the drop of a hat

  • FLEXIBILITY is key…not tangible supports
Benefits & Plan for Sustainability

• Illustrated need for looking at a new training category for medium term trainees
• Confirmed that we need to explore on-line training to increase access

Project’s next step – looking at types and features of distance education tools that can be used for on-line training that is accessible to family members and other trainees

Sustainability will be through annual recruitment meetings and through the inclusion and listening to the voices of family member faculty and trainees during planning activities for next 5 year funding cycle
Training, Supporting, and Engaging Family Members as Participants in LEND Programs
* Family/advocates included as speakers and fellows since our initial year
* Desert Southwest: unique cultural groups
* Family/advocate and professional partnerships important in enhancing culturally competent healthcare practices
Primary Issues Addressed

* Need for additional infrastructure and supports:
  * To ensure family/advocate fellows engagement
  * To ensure family/advocate fellows receive as much benefit from the program as they provide

* Lower levels of educational attainment

* Robustness of material and discussion versus content that is accessible to all students

* Removal of perceived barriers to family/advocate active engagement
Goal

* Develop a family didactic seminar and an educational toolbox of supplementary materials that will increase and support the engagement of family/advocate fellows.
Objectives

* Objective 1: Design a 3-hour seminar highlighting the family perspective facilitated by the family faculty member with assistance from family and advocate fellows to begin in Year 2015-2016.

* Objective 2: Create a strategic plan for development of an intake assessment and educational toolbox that mentors can use to increase content accessibility and improve fellow participation in AZLEND didactic seminars and related activities.
Activity 1.1: Send AZLEND Family faculty for training to the Parent Professional workshop developed through the University of North Carolina, Carolina Institute for Developmental Disabilities
Activity 1.2: Revise workshop to meet needs of ArizonaLEND fellows

‘Powerful Partnerships’
A Parent Professional Workshop
Activity 1.2: Workshop Activities

“Unpacking”
--Multisensory, reflective listening activity

--Power of the narrative in building the relationship between healthcare providers and parents
Activity 1.3
Create curriculum and facilitators guide for future implementation
Activity 2.1: Conduct Interviews

Activity 2.2: Create ArizonaLEND Intake Assessment Tool
Activity 2.2: ArizonaLEND Intake Assessment Tool (pg.2)
Areas needing extra support in future:
  * Research, research methods, epidemiology, genetics, advocacy and disability studies
  * Overall: empowered to participate during class discussions and group projects
  * Family perspective well-represented
  * Area of need: more families/advocates to present their own stories
Activity 2.3: The Educational Toolbox
Activity 2.3: The Educational Toolbox
Challenges/Unexpected Results

* Timesaving resource for us all
* Interprofessional team--in-depth understanding of the details of each other’s professions.
* Educational Toolbox and the interconnectedness of LEND disciplines
Benefits & Sustainability

* **Benefits:** Workshop adds depth to ArizonaLEND curriculum, Educational toolbox increases confidence
* **Dissemination:** ITAC Training Toolbox, ArizonaLEND website
* **Sustainability:** Workshop conducted in March 2016, Train-the-trainer event, Educational Toolbox updated annually
Questions?
Lessons for the Future

• Making family members feel comfortable

• Flexibility and convenience

• New models for support and engagement