

The LEND Family Involvement Survey: Findings and Implications from Year One

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Background:

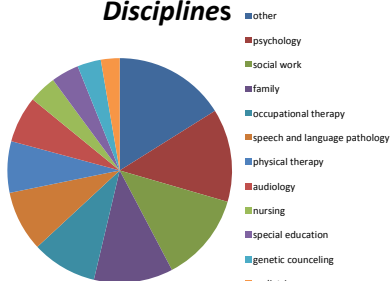
The LEND Family Discipline Network wanted to learn about the multiple roles that families play in educating all LEND trainees and the impact of this family involvement.

- In 2012 - We developed a pilot. Nine LENDs participated in the survey pilot.
- In 2013-
 - The LEND Family Network, in conjunction with the CA-LEND program (an input from the Training Directors Committee), analyzed the pilot survey results and developed the 2013 on-line survey.

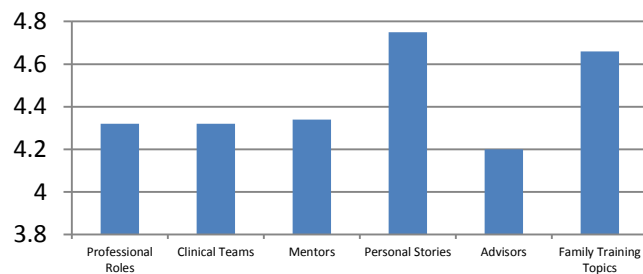
All LEND Directors were sent an announcement of the survey and an instructions-to-participant sheet to send to graduating LEND fellows. 187 fellows from 24 LENDs participated in the survey.

"Family participation in the LEND training program clarified my views of family and disability. It is crystal-clear to me that a family is always a family first and foremost - and I don't know that it would have been the case if not for the opportunity to learn directly from and with families."

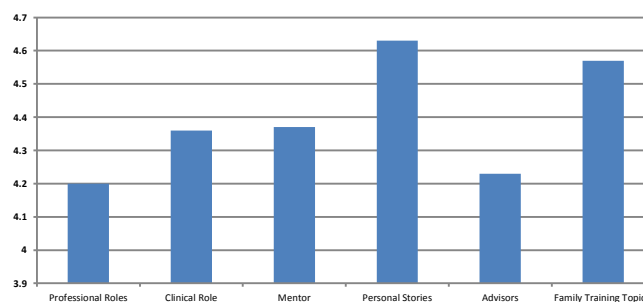
Disciplines



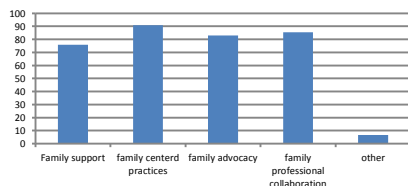
How important to you were...



What is the likely impact of...



Respondents received training in



Participating LENDs:

- Boling Center for Developmental Disabilities, Memphis, TN
- CA-LEND, Los Angeles, CA
- Center for Child Health and Development, Kansas City, KS
- Center for Disability, Sioux Falls, SD
- Center for Human Development, Anchorage, AK
- Cullen International Research Center and Spaulds Clinic, Birmingham, AL
- Curran Kennedy Center, Washington, DC
- Institute for Community Inclusion, Boston, MA
- Iowa University Center for Excellence in Disabilities, Iowa City, IA
- John Fitzgerald Kennedy Partners, Aurora, CO
- LEND of Pittsburgh at the University of Pittsburgh, Pittsburgh, PA
- LEND Program at Cincinnati Children's Hospital Medical Center, Cincinnati, OH
- LEND Without Walls, University of Alaska at Anchorage, Anchorage, AK
- MRI-LEND, Minneapolis, MN
- Muscarello Institute for Genetics and Rehabilitation, Omaha, NE
- New Hampshire LEND Program, Lebanon, NH
- Neurocenter LEND, Columbia, SC
- Oklahoma LEND, Oklahoma City, OK
- Oregon Institute on Disability & Development, Portland, OR
- Partners for Inclusive Communities, North Little Rock, AR
- Partnership for People with Disabilities, Richmond, VA
- Riley Child Development Center, Indianapolis, IN
- Rose F. Kennedy Center, Boston, MA
- SC LEND, Charleston, SC
- Strong Center for Developmental Disabilities, Rochester, NY
- The University of Arizona LEND (AZLEND), Tucson, AZ
- TPS for Kids, Columbia, MD
- University of Illinois LEND, Chicago, IL
- University of New Mexico, Albuquerque, NM
- University of Washington LEND Program, Seattle, WA
- USLEND, Salt Lake City, UT
- Vanderbilt LEND, Nashville, TN
- VT Interdisciplinary Leadership Education for Health Professionals, Burlington, VT
- Westchester Center, Madison, WI
- Westchester Institute for Human Development, Valhalla, NY

Discussion and Next Steps

Four issues arose which require further exploration and/or revision to the survey:

- Due to delays in the IRB process, the survey was not sent to LEND directors until the end of April. This was too late for some centers to participate in the survey. Therefore we are treating 2013 as a pilot.
For 2014, the survey will be sent in March.
- While we know how many trainees opened the survey and responded to each survey question, we do not know how many trainees received the survey.
For 2014, survey, we will ask each LEND to provide us with the number of fellows who were asked to participate in the survey.
- It was our intent to make the survey results available participating LENDs. However, a concern has developed that programs with fewer participants may be able to identify the responses of individuals.
For 2014, we will share general responses, but not demographic information for individual respondents.
- 14 participants did not identify which LEND site they attended. Therefore, we do not have an accurate record of how many programs participated.
For 2014, the LEND site will be a required field, with an assurance that site demographics will not be shared.

"I was able to see what this world looked like from a family who held different views and values than my own. This radically affected my perspective of "best" for the family."

This poster is dedicated to
Ruth Roberts, Ed.D.

Acknowledgements:

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The Maternal Child Health Bureau

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