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

1 Cohen, et al. (2006). *Family Discipline Competencies: Leadership Education in Neurodevelopmental and Related Disabilities*. Retrieved from https://www.aucd.org/docs/lend/family_faculty/famcomp/competencies2006.pdf

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.

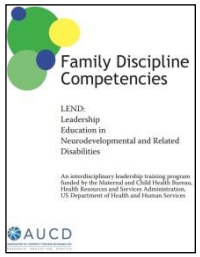
Session Overview

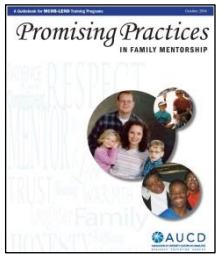
- Explore the traditional roles of family members within LEND
- Identify the primary issues family members face as it relates to their participation in interdisciplinary training
- Highlight two FAST projects that addressed these issues in innovative ways
- Discuss lessons learned, promising practices, 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."[2]

- 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

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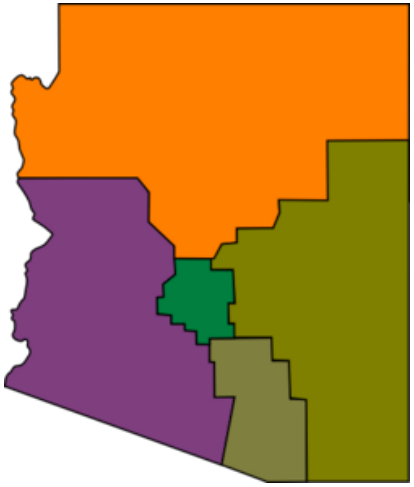
* Family/advocates included as speakers and fellows since our initial year
* Desert Southwest: unique cultural groups
* Family/advocate and professional partnerships important in enhancing culturally competent healthcare practices



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.

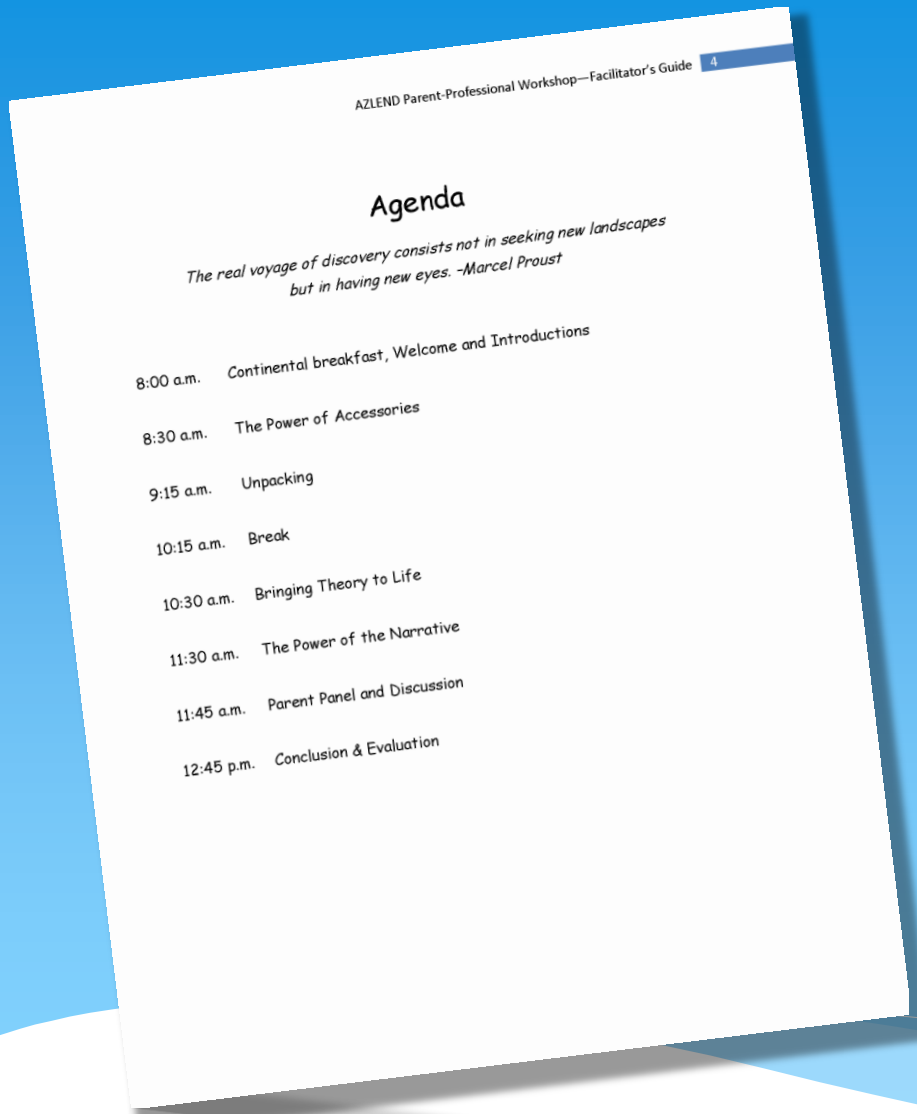
Objectives

* 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.

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*



AZLEND Parent-Professional Workshop—Facilitator's Guide 4

Agenda

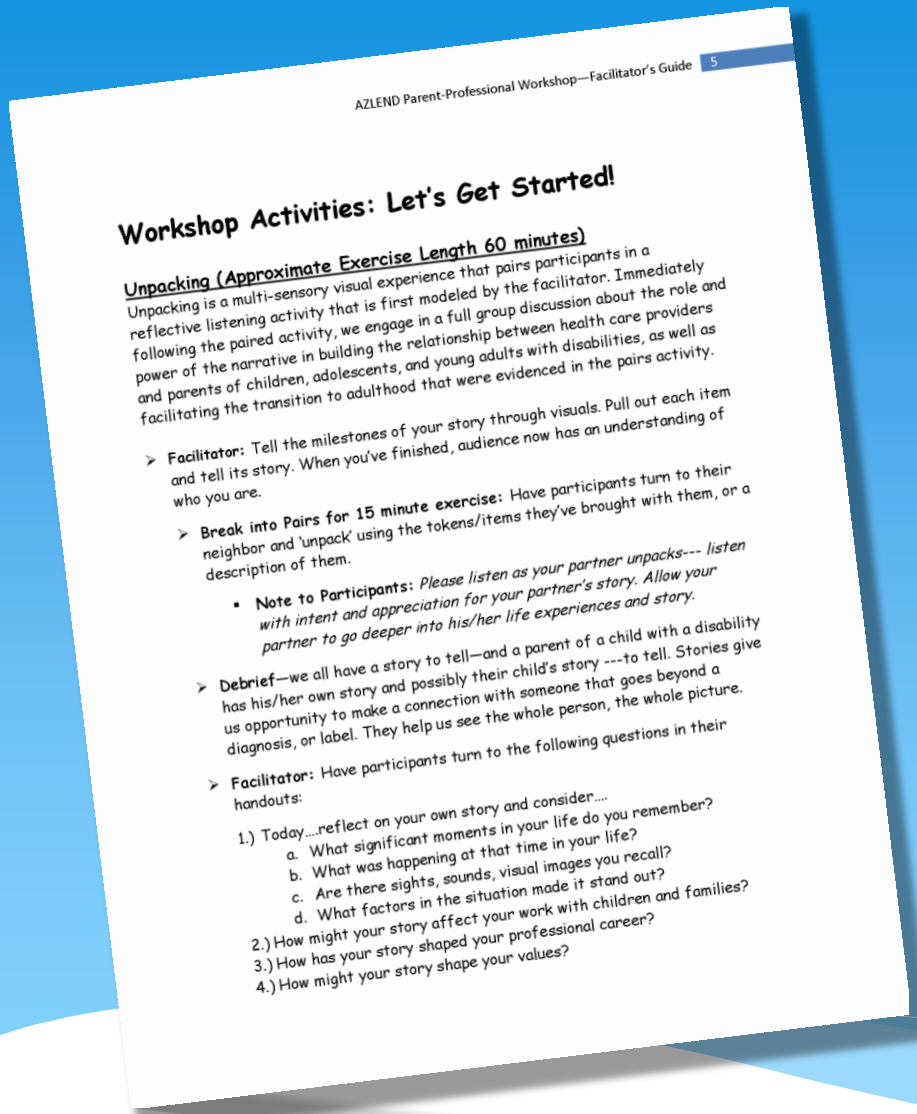
The real voyage of discovery consists not in seeking new landscapes but in having new eyes. -Marcel Proust

8:00 a.m.	Continental breakfast, Welcome and Introductions
8:30 a.m.	The Power of Accessories
9:15 a.m.	Unpacking
10:15 a.m.	Break
10:30 a.m.	Bringing Theory to Life
11:30 a.m.	The Power of the Narrative
11:45 a.m.	Parent Panel and Discussion
12:45 p.m.	Conclusion & Evaluation

Activity 1.2: Revise workshop to meet needs of ArizonaLEND fellows

'Powerful Partnerships'

A Parent Professional Workshop



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Workshop Activities: Let's Get Started!

Unpacking (Approximate Exercise Length 60 minutes)

Unpacking is a multi-sensory visual experience that pairs participants in a reflective listening activity that is first modeled by the facilitator. Immediately following the paired activity, we engage in a full group discussion about the role and power of the narrative in building the relationship between health care providers and parents of children, adolescents, and young adults with disabilities, as well as facilitating the transition to adulthood that were evidenced in the pairs activity.

- **Facilitator:** Tell the milestones of your story through visuals. Pull out each item and tell its story. When you've finished, audience now has an understanding of who you are.
- **Break into Pairs for 15 minute exercise:** Have participants turn to their neighbor and 'unpack' using the tokens/items they've brought with them, or a description of them.
  - **Note to Participants:** *Please listen as your partner unpacks--- listen with intent and appreciation for your partner's story. Allow your partner to go deeper into his/her life experiences and story.*
- **Debrief**—we all have a story to tell—and a parent of a child with a disability has his/her own story and possibly their child's story ---to tell. Stories give us opportunity to make a connection with someone that goes beyond a diagnosis, or label. They help us see the whole person, the whole picture.
- **Facilitator:** Have participants turn to the following questions in their handouts:

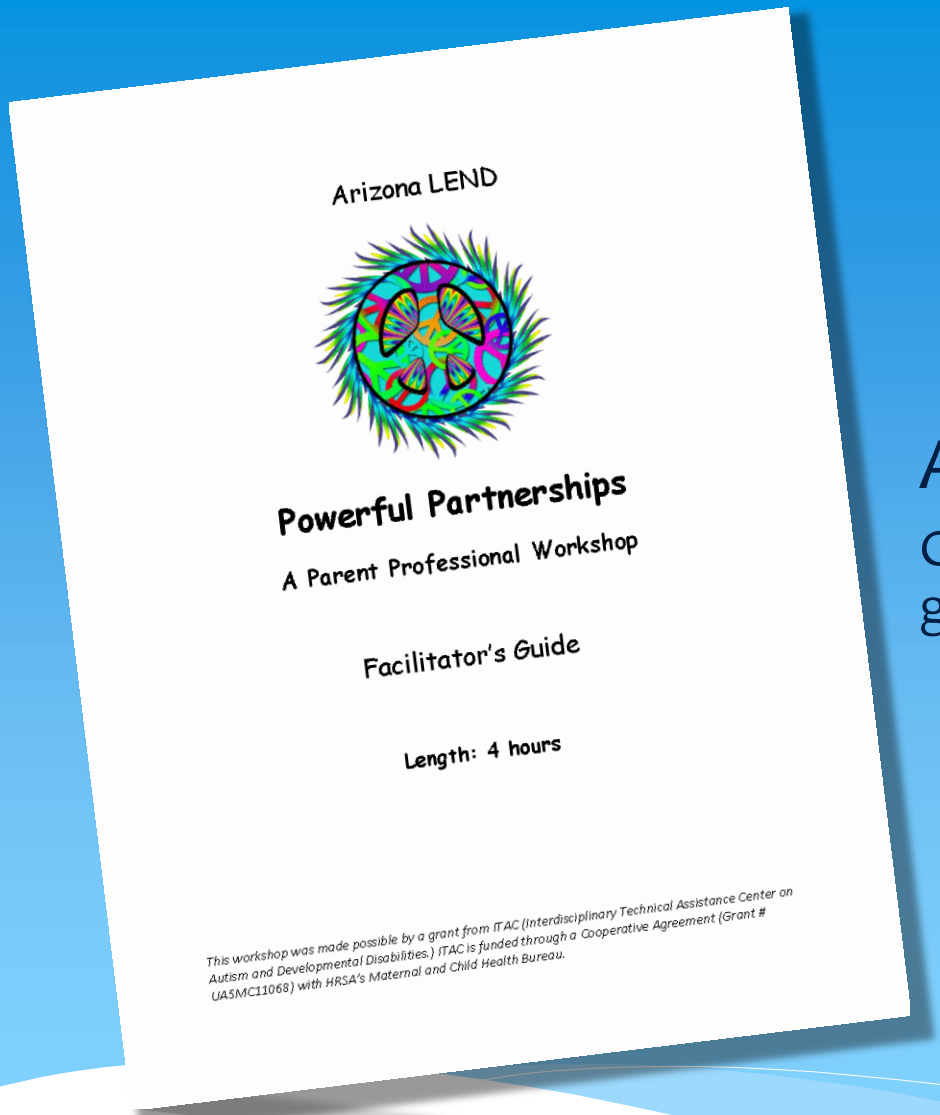
1.) Today….reflect on your own story and consider….
   a. What significant moments in your life do you remember?
   b. What was happening at that time in your life?
   c. Are there sights, sounds, visual images you recall?
   d. What factors in the situation made it stand out?
2.) How might your story affect your work with children and families?
3.) How has your story shaped your professional career?
4.) How might your story shape your values?

Activity 1.2: Workshop Activities

"Unpacking"

--Multisensory, reflective listening activity

--Power of the narrative in building the relationship between healthcare providers and parents



Arizona LEND

Powerful Partnerships

A Parent Professional Workshop

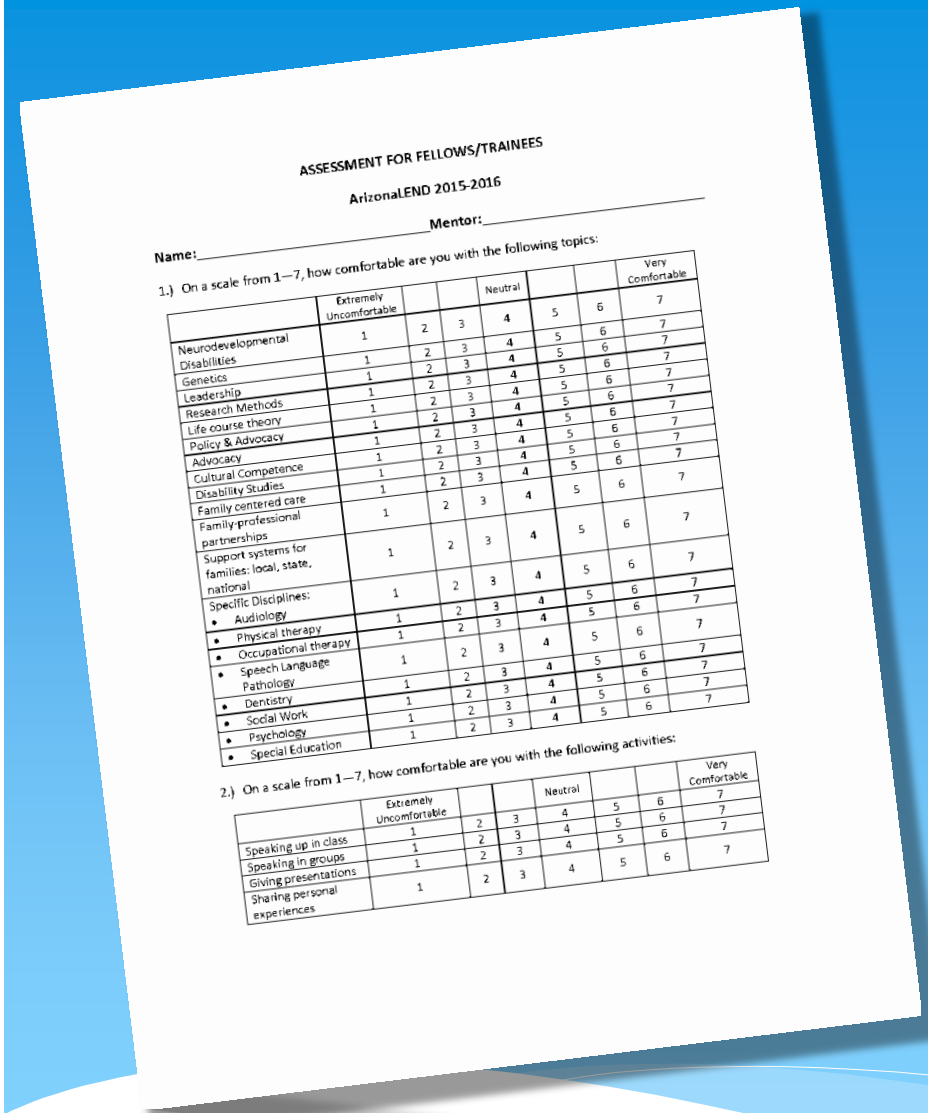
Facilitator's Guide

Length: 4 hours

This workshop was made possible by a grant from ITAC (Interdisciplinary Technical Assistance Center on Autism and Developmental Disabilities.) ITAC is funded through a Cooperative Agreement (Grant # UA5MC11068) with HRSA's Maternal and Child Health Bureau.

Activity 1.3

Create curriculum and facilitators guide for future implementation



ASSESSMENT FOR FELLOWS/TRAINEES

ArizonaLEND 2015-2016

Name:_____ Mentor:_____

1.) On a scale from 1—7, how comfortable are you with the following topics:

	Extremely Uncomfortable			Neutral			Very Comfortable
Neurodevelopmental Disabilities	1	2	3	4	5	6	7
Genetics	1	2	3	4	5	6	7
Leadership	1	2	3	4	5	6	7
Research Methods	1	2	3	4	5	6	7
Life course theory	1	2	3	4	5	6	7
Policy & Advocacy	1	2	3	4	5	6	7
Advocacy	1	2	3	4	5	6	7
Cultural Competence	1	2	3	4	5	6	7
Disability Studies	1	2	3	4	5	6	7
Family centered care	1	2	3	4	5	6	7
Family-professional partnerships	1	2	3	4	5	6	7
Support systems for families: local, state, national	1	2	3	4	5	6	7
Specific Disciplines:	1	2	3	4	5	6	7
• Audiology	1	2	3	4	5	6	7
• Physical therapy	1	2	3	4	5	6	7
• Occupational therapy	1	2	3	4	5	6	7
• Speech Language Pathology	1	2	3	4	5	6	7
• Dentistry	1	2	3	4	5	6	7
• Social Work	1	2	3	4	5	6	7
• Psychology	1	2	3	4	5	6	7
• Special Education	1	2	3	4	5	6	7

2.) On a scale from 1—7, how comfortable are you with the following activities:

	Extremely Uncomfortable			Neutral			Very Comfortable
Speaking up in class	1	2	3	4	5	6	7
Speaking in groups	1	2	3	4	5	6	7
Giving presentations	1	2	3	4	5	6	7
Sharing personal experiences	1	2	3	4	5	6	7

Activity 2.1: Conduct Interviews

Activity 2.2: Create ArizonaLEND Intake Assessment Tool

Activity 2.2: ArizonaLEND Intake Assessment Tool (pg.2)

3.) On a scale from **1—7**, how comfortable are you following assignments/completing projects:

	Extremely Uncomfortable			Neutral			Very Comfortable
Letter of Intent	1	2	3	**4**	5	6	7
Leadership Project	1	2	3	**4**	5	6	7
Group research project	1	2	3	**4**	5	6	7
Family mentor project	1	2	3	**4**	5	6	7

4.) One of the strengths of the AZLEND program is the richness of conversation, and exploration of subjects that often begins with fellows sharing their own experiences. What do you want to share with the other fellows?

5.) Where are the areas you 'stretch' as a person?

6.) What strengths do you bring to the AZLEND program?

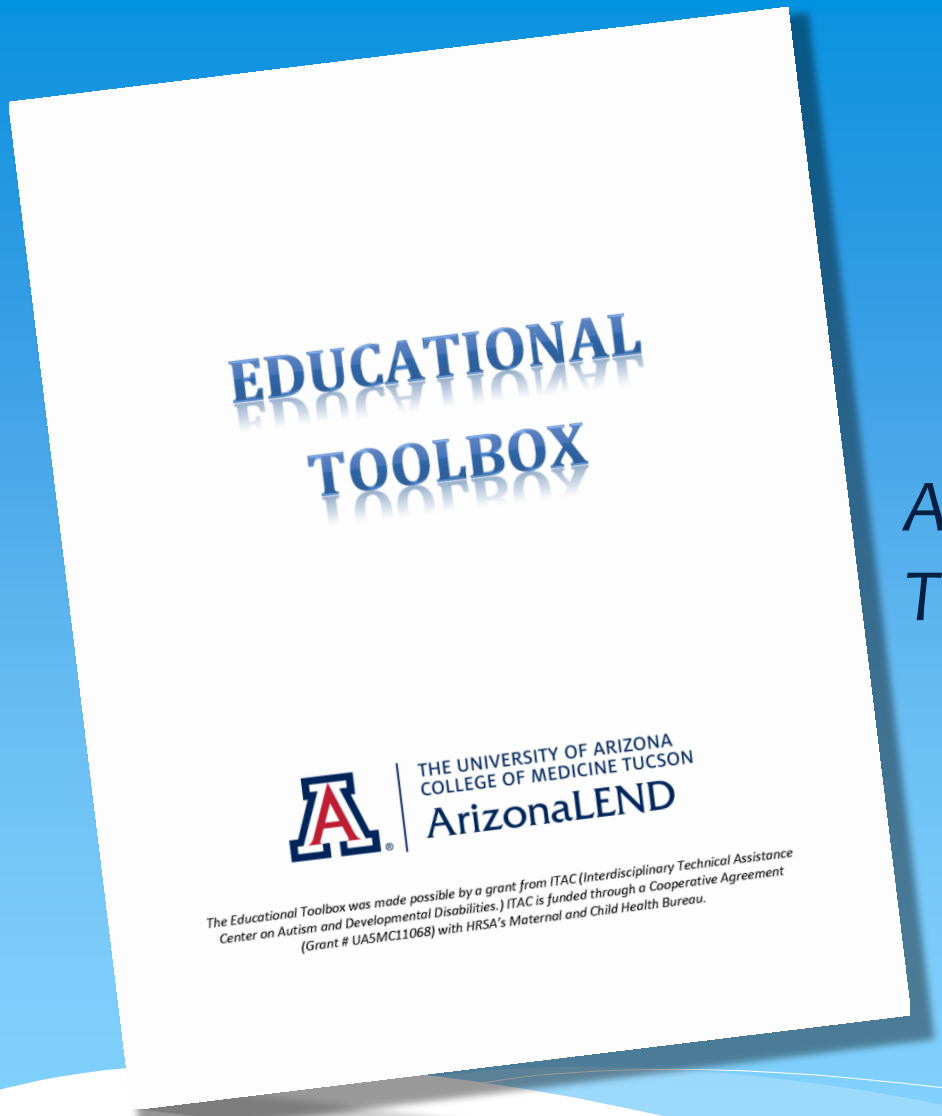
7.) Based on what you know about the LEND program, where do you feel you can contribute?

8.) What are your biggest fears?

9.) How can we help you succeed?

Survey Responses

* 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

Genetics

Definition:

Genetics research studies how individual genes or groups of genes are involved in health and disease. Understanding genetic factors and genetic disorders is important in learning more about preventing birth defects, developmental disabilities, and other unique conditions among children.

Some genetic changes have been associated with an increased risk of having a child with a birth defect or developmental disability. Genetics also can help us understand how birth defects and developmental disabilities happen.

People get (inherit) their *chromosomes*, which contain their *genes*, from their parents. Chromosomes come in pairs and humans have 46 chromosomes, in 23 pairs. Children randomly get one of each pair of chromosomes from their mother and one of each pair from their father. The chromosomes that form the 23rd pair are called the sex chromosomes. They decide if a person is male or female. A female has two X chromosomes, and a male has one X and one Y chromosome. Each daughter gets an X from her mother and an X from her father. Each son gets an X from his mother and a Y from his father. *Centers for Disease Control & Prevention.*

Websites

- Educational Materials about Genetics and Genomics: This National Human Genome Research Institute website offers a talking glossary of genetic terms, fact sheets, and other genetics-related resources.
- G2C2 Genetics/Genomics Competency Center for Educators : The mission of G2C2 is to provide high quality educational resources for group instruction or self-directed learning in genetics/genomics by health care educators and practitioners.
- Genes in Life: Genes in Life was created by Genetic Alliance to answer your questions about health and genetics.
- Six Things Everyone Should Know About Genetics: This American Society of Human Genetics website provides basic genetics information and resources.

Articles, Guides, Additional Resources

What you should know about genetics.

Life Course Theory

Definition:

Life Course looks at health as an integrated continuum and suggests that a complex interplay of biological, behavioral, psychological, social, and environmental factors contribute to health outcomes across the course of a person's life. It builds on recent social science and public health literature that posits that each life stage influences the next and that social, economic, and physical environments interacting across the life course have a profound impact on individual and community health. *HRSA, MCHB (Health Resources & Services Administration, Maternal & Child Health Bureau.)*

Life Course Perspective for Families of Children and Youth with Special Health Care Needs: Viewing events through a life-course perspective can be useful to better understand the experiences of families with children and youth with

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