

**HOW LEND PROGRAMS
DEVELOP FAMILY LEADERS
WHO ADVOCATE FOR
INCLUSION IN COMMUNITY
LIFE FOR INDIVIDUALS
WITH DISABILITIES AND
FAMILIES**

The LEND
Family
Discipline
Network

AGENDA

- **Welcome and introduction- Fran Goldfarb**
- **Using the LEND Curriculum to Develop Family Trainees as Leaders**
 - **Sharing My Story – Stephanie Coleman**
 - **Family Involvement - Barbara Levitz**
 - ***From Families as Mentors to Leaders as Mentors- Dori Ortman***
 - ***Shadowing a Family Resource Navigator – Mark Smith, Jonna Mulvaney***
- **Small Group Discussion**
- **Share Back – Fran Goldfarb**
 - **Examples of Family Trainee Leadership**

USING THE LEND CURRICULUM TO DEVELOP FAMILY TRAINEES AS LEADERS

Sharing My Story

**Stephanie Coleman,
Family Support Coordinator
Kansas Lend**

USING THE LEND CURRICULUM TO DEVELOP FAMILY TRAINEES AS LEADERS

How The LEND **Policy & Advocacy Curriculum Module** At WIHD Tailors The Parallel Curriculum For Clinical Discipline Peers In Order To Build Knowledge And Skills In **Family Leadership** For Family Trainees



Barbara Levitz, MS Ed
Director-Family Partnerships Training
LEND NY/Valhalla

Tailoring Policy & Advocacy Curriculum Assignments and Activities

- Review and compare legislative priorities of AUCD and a national *family* organization (such as Family Voices). Identify and select a current legislative policy initiative that is of importance to you **and other families**. Track this policy initiative weekly for three months; and share-back at a LEND session.
- Participate in a structured group interview with a designated *family member* who is a local, state or national community advocacy leader; and participate in a group report-back presentation.

- Read and evaluate an assigned ***family support*** policy brief. Identify the type of policy-makers who you think should hear your personal testimony. Prepare and present a two-minute public testimony “elevator speech” to a “mock” policy-makers panel who will provide feedback.



USING THE LEND CURRICULUM TO DEVELOP FAMILY TRAINEES AS LEADERS

From
“Families as Mentors to
“Leaders as Mentors

Dori Ortman
Family Faculty
The LEND Center of Pittsburgh

USING THE LEND CURRICULUM TO DEVELOP FAMILY TRAINEES AS LEADERS

Shadowing a Family Resource Navigator

**Jonna Mulvaney
Family Faculty
Sherlock Center on
Developmental Disabilities
@ Rhode Island College**

**Mark Smith, MS
Assistant Professor
Munroe-Meyer Institute for
Genetics and Rehabilitation
Omaha, NE**

Success of our Program

Multiple Clinics occurring across disciplines

One of our Trainee requirements:

- a) participation in clinical observations.

Title V and Department of Education introduced

- a) Placing peer navigators in medical clinics is advantageous

Family trainees report value in observing clinics with navigators present and shadowing

connection advocate
compassion equality partner empathy
collaboration voice
relationship engaged
advocacy empowered responsibility



SMALL GROUP DISCUSSION

Please break up into small groups to discuss your programs strategies and successes in **Developing Family Leaders Who Advocate For Inclusion in Community Life For Individuals With Disabilities And Families**

SHARE BACK

FAMILY DISCIPLINE LEADERS



Anne Marie Cellante
2014-15
WIHD/LEND NY-Valhalla

Lynn Pukylo
2013-14
LEND Pittsburgh



Yudi Bennett
2006-08
CA-LEND, Los Angeles



FAMILY DISCIPLINE LEADERS



Deborah Golding
2016-2017
RI LEND



Kelly Stephans
2017-18
LEND Pittsburgh



Jonna Mulvaney
2016-2017,
RI LEND

FAMILY DISCIPLINE LEADERS



Anne Marie Cellante 2014-15 WIHD/LEND NY-Valhalla

Anne Marie Cellante, M.S. Ed. has assumed leadership roles in the Family Support Services Advisory Council, serving as a chairperson to her local council, and currently as Statewide Representative for Westchester County. She is an appointed member of the Local Early Intervention Coordinating Council and on the board of the SEPTA at her son's school. Anne Marie currently works part-time as an assistant coordinator of the *Improving Family Centeredness Together* (IFaCT) project, a collaboration of the NYS Department of Health and Westchester Institute for Human Development which seeks to improve the Early Intervention experience for families in New York State. Since graduating from LEND, as the parent of three children (triplets) with disabilities, she has continued to participate each year on family panels and as a mentor family (for the Family Mentorship experience). Anne Marie is also completing her graduate coursework for teaching certification in Special Education.

FAMILY DISCIPLINE LEADERS



Lynn Pukylo , 2014 LEND

After graduating from LEND, Lynn accepted a position of Director of Transition at Lifesteps, an organization that provides services for children, families, and adults with special needs designed to encourage growth, independence, confidence and dignity. She says that LEND gave her the tools and confidence she needed to pursue her passion.

FAMILY DISCIPLINE LEADERS



Kelly Stephans, 2018 LEND Pittsburgh

Following her graduation from LEND, Kelly accepted a position in the special education department of one of Pittsburgh's suburban school districts, where she is making a real difference in the lives of students with special needs. She states that she uses the strategies learned in her LEND training on a daily basis.

FAMILY DISCIPLINE LEADERS



Yudi Bennett, MA2006-08 CA-LEND, Los Angeles

Yudi Bennett is a passionate advocate for all those with special needs, especially young adults with autism. She is the co-founder and past director of Exceptional Minds an innovative visual effects and animation school and

studio for artists on the Autism Spectrum. Exceptional Minds artists work on such hit movies as “Black Panther” and “Star Wars: The Last Jedi.” Her dream is to see all young adults with ASD in meaningful jobs, leading independent and productive lives.

Yudi comes from the motion picture world. She has been a member of the Directors Guild of America since 1978 and received their Frank Capra Lifetime Achievement Award in 2003. She is the founder and past president of the Foothill Autism Alliance. Yudi is inspired everyday by her son, Noah Schneider, a young artist who was diagnosed with ASD in 1997

FAMILY DISCIPLINE LEADERS



Deborah Golding 2016-2017, RI LEND

Deb Golding:

Using the strategies learned in the RI LEND training on a daily basis, Deb enhanced her position as the Rhode Island Dept. of Health Adolescent ,Health Transition Program Coordinator.

Her role is to assist adolescents with special healthcare needs and disabilities to transition and successfully transfer to the adult systems of primary and specialty care, education, employment, and insurance. She is making a real difference in the lives of Youth with special healthcare needs in Rhode Island. She is also one of the creators of Dare to Dream. RI

FAMILY DISCIPLINE LEADERS



Jonna Mulvaney 2016-2017, RI LEND

After graduating from RI LEND in 2017, Jonna accepted the role of Family Faculty, overseeing 3-4 Family Trainees yearly. Jonna accredits LEND for her

receiving the newly created position as the Patient Family Centered Care Coordinator for Hasbro Children's Hospital. This role is responsible for Family Support Service recovery and bringing the family voice and perspective to the healthcare team. She was appointed Co-Chair of the 15-member HCH Family Advisory Council, and was integral in defining a process for adding parents to Hospital Acquired Conditions teams (HAC's). Jonna also works part-time as an Parent Navigator for the Children's Neurodevelopment Center, supporting families in obtaining resources and support for their newly diagnosed children.

PRESENTERS

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