



AUUCD

Life After LEND:

**Family and Self Advocacy Fellows
Go from Lived Experience to
Leaders to Agents for Change**

LEND Family Discipline Network

Persons With Disabilities Workgroup

Presenters

Jack Brandt, , MS: VA - Partnership for People with Disabilities, UCEDD/LEND

Alicia Curran, BS, Grad Cert: University of Missouri LEND

Sarah DeMaio, MSW: AUCD

Fran Goldfarb, MA, MCHES, CPSP: CA- USC UCEDD/LEND

Michael Hoenig , MA: IA - Center for Disabilities and Development, UCEDD/LEND

Dori Ortman: PA - UCLID Center, LEND

Mark Smith, MS: NE - Munroe-Meyer Institute of Genetics & Rehabilitation, UCEDD/LEND

LEND Family and Self Advocacy Fellows are Different

Not Clinical Disciplines

No University Course of Study

Different Profiles, Strengths and/or Challenges

May Require Specialized Mentorship

Less Clear Post-LEND Career Trajectory

This Session

Interactive

Highlight Examples of Trainee Post-LEND
Accomplishments

Small Group Discussion

- Supporting trainees in LEND and beyond –Mike
- Beyond the personal to the community–Alicia
- Recruiting Trainees who have a vision–Sarah

Large Group Discussion

Who are we and why are we here?



Mark Smith, MS

Family Faculty
Nebraska LEND
Munroe-Meyer Institute
University of Nebraska Medical Center



Jack Brandt, MS

Disability Advocacy Faculty
Virginia LEND
Partnership for People with Disabilities
Virginia Commonwealth University

Former co-chairs of COLA

Sustain Leadership Through the Lens of Lived Experience

Successes

- Creating leadership opportunities in AUCD network
- Meaningful participation in system change activities
- Developing leaders who are available to work in advocacy, service, and support roles in community programs and schools
- Supports trainees in identifying paths to allow them to attain their goals

Areas of Improvement

- Better define the roles of family and disability advocacy trainees as equal members of disciplines within the disability field
- Better identify options and direct trainees to opportunities, either paid or unpaid
- Better support the trainees once they have completed their programs

Alexis Nichols

Virginia LEND Graduate

Alexis completed both the VaLEND medium and long-term tracks

Leadership project: Alexis wrote and produced a prototype of a children's book *Disability is OK*, because she saw a lack of disabled authors

Interests: Authoring additional children's books based on disability; public speaking; and conducting training for other people with disabilities



Molly Peers

Virginia LEND Graduate

Molly completed the VaLEND medium track

Leadership project: Developed a tip sheet for trainers who use augmented and alternative communication (AAC) device. She discovered a lack of resources for people who use AAC that want to become trainers like her

Interests: Training other people with disabilities; accessible travel; and her pets



Cristy James: 2009 LEND Family Trainee Riley Child Development Center – Indiana LEND

Cristy James is the parent of two amazing young adults with neurodevelopmental disabilities. She currently works as the Data Coordinator and Family Discipline Coordinator at the Indiana LEND program. While happiest playing with numbers, Cristy does a fantastic job of supporting LEND research, evaluation, and training efforts and always enjoys sharing her family perspective.



Rylin Rodgers: 2008 LEND Family Trainee

Riley Child Development Center – Indiana LEND

Rylin Rodgers is the Director of Public Policy at the Association of University Centers on Disabilities where she works on federal policy and legislative issues that affect people with developmental disabilities and their families. Prior to working at AUCD, Rylin served as the Training Director and Family Leadership Coordinator for the Riley Child Development Center (Indiana's LEND), and was a founding board member of Family Voices Indiana. Both as a parent and as a professional, Rylin has extensive expertise on topics including special education regulations, public and private health care financing and family/professional partnerships. Her personal and professional experiences combine to provide a unique perspective on the impact of policy and of systems issues on the "end users."



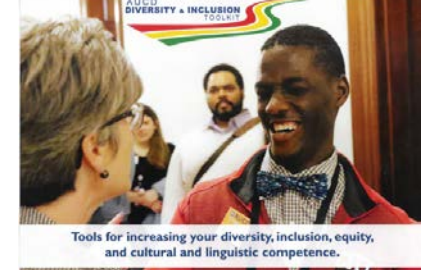
Melody Cooper: 2017 LEND Self-Advocate Trainee Riley Child Development Center – Indiana LEND

Melody Cooper is a Self-Advocate Specialist at the Arc of Indiana and the Self-Advocate Discipline Coordinator for the Indiana LEND program. One of the first Indiana LEND self-advocate trainees, Melody has taken a leadership role in defining what the roles, responsibilities, and possibilities can be for all self-advocate trainees that have followed her into the program. Melody serves as an amazing mentor to many people and leads many presentations, trainings, and advocacy sessions throughout the state.



Edward Esbeck: 2007 Self-Advocacy Trainee University of Iowa Center for Disabilities and Development-Iowa UCEDD

Edward (Ed) Esbeck is employed as a self-advocacy coordinator with the University of Iowa Center for Disabilities and Development-Iowa UCEDD. As the Iowa LEND's first self-advocacy trainee (2017), Esbeck quickly achieved recognition as an eloquent speaker by telling his story at the AUCD and AMCHP national conferences. In 2018, he returned as an intermediate LEND trainee, mentoring the new self-advocacy trainee and students enrolled in the Iowa City Community School District's transition program. In May of 2019, Esbeck received the Alfred Healy Leadership Award in Developmental Disabilities, providing the funding which allowed him to realize his lifelong dream to return to his native Uganda where he completed two summer internships and shared his experiences related to self-advocacy and employment. At the ripe age of 22, Esbeck has authored numerous publications, including a handbook for entering LEND self-advocacy trainees, presentations on employment for youth with disabilities, and a video welcoming students to the Center for Disabilities and Development's Transition Clinic.



Yudi Bennett, MA: 2006-08

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

Mark Tapia, MA: 2017-18 Self-Advocacy Trainee

University of Missouri LEND

LEND Graduate: 1st Missouri LEND Self-Advocate

Since LEND Graduation....

- Autism Learning Health Network Self-Advocacy Committee Co-Lead
 - 1st Self-Advocate of the Network!
- PhD student at University of Texas Austin
 - Special Education
- ECHO Autism Expert Hub Team Member
 - Transition to Adulthood- National Program



Amy Longenecker: 2015-16 Family
Trainee
University of Missouri LEND



Since LEND Graduation....

- Autism Learning Health Network (ALHN)
Family Representative (National Program)
- University of Missouri Quality Improvement
Team as a Family Representative
- ECHO Autism Expert Hub Team Member
– Early Intervention Program