

The University of Cincinnati Center for Excellence in Developmental Disabilities (UCCEDD)

2016-2017 Annual Report

Letter from the Director



Dear Friends and Colleagues,

I am happy to share with you our Annual Report for Fiscal Year 2017 for the University of Cincinnati Center for Excellence in Developmental Disabilities (UCCEDD) in the Division of Developmental and Behavioral Pediatrics at Cincinnati Children's Hospital Medical Center. It provides an overview of the work we have done over the last year to improve the lives of children, adolescents and adults who have developmental disabilities and their families.

We value our community connections and are grateful for our partnerships. Thank you for the trust you put in us to improve communities, services and policies for individuals with disabilities. Our faculty partners do amazing work in research and interdisciplinary training, which drives new knowledge for diagnosis, treatment, interventions and best practice; and increases knowledge and skills of professionals who support people with disabilities and their family members.

In FY17 we expanded our transition training and one-on-one support to southern, central and northern Ohio. We also focused heavily on Family Support. Through collaboration with Ohio's Department of Developmental Disabilities (DODD) and the Nisonger Center at The Ohio State University, we implemented the Charting the LifeCourse Framework across the state. We also established regional Communities of Practice driven by family members' needs and ideas on how to support each other.

We have been active in informing local, regional, state and national policy work, expanded research in the areas of Down Syndrome and ADHD, and have shared products and information with thousands of university and hospital colleagues, professionals, family members, self-advocates and policymakers.

Our work is informed by our Community Advisory Council, community colleagues as well as current best practice, research and disability policy. We look at gaps that need to be bridged, explore how to address unmet needs and respond to current issues.

Thank you for the support you have provided in 2017 and for your partnership in this important work. We look forward to continuing our work in order to achieve our vision that all people, including people with disabilities and their families, fully participate in society and live healthy, safe, self-determined and productive lives!

With much appreciation,

Ilka

Interdisciplinary Training



The 2016-2017 LEND Class

Our Cincinnati LEND (Leadership Education in Neurodevelopmental and related Disabilities) program improves the health of infants, children and adolescents with, or at risk for, neurodevelopmental and related disabilities by providing interdisciplinary training to future professionals in the field.

"LEND has provided me with skills to advocate for my son at the next level and to teach him how to advocate for himself. I've learned to focus on his wants, needs, desires and strengths."

LEND family trainee

Out of the 100 LEND trainees:
27% identified as a minority
25% identified as male
21% identified as a family member of a person with a disability
4% identified as a person with a disability

"As a result of the LEND program, I've become a better therapist. I have identified the type of leader I want to be. My understanding of inclusion has been challenged and is growing me more into the person I want to become."

LEND trainee

Community Education & Collaboration

The UCCEDD conducted
49
community training activities for
1,346
family members and caregivers, self-advocates, professionals and students on employment, transportation, health, quality of life, education, early intervention and others

The **Empowering Families Symposium** drew a record 325 attendees and this year focused on self-advocacy.

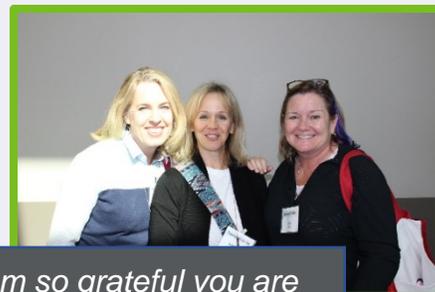


Lighthouse Youth & Family Services, Vendor

Transition Bootcamp Conference and Booster Sessions

The conference in the fall and subsequent monthly booster sessions continue to grow. Over **400** family members and educators attended the conference and due to its popularity, we continue to offer booster sessions that address one transition topic at a time in more detail. An average of **50** parents/caregivers attend each month. This FY, we were able to expand Transition Booster Sessions to the Cleveland area in NE Ohio, with a great response from family members. Each of the transition sessions in NE Ohio has **80-100** people attend. Sessions are a collaboration of the UCCEDD, Ohio F2F, two main health systems from Cleveland and some parent organizations. Due to the success of booster sessions in SW and NE Ohio, central Ohio (Columbus area) started transition booster sessions in the central part of the state in the fall of 2017. These transition trainings allow individuals with developmental disabilities to experience greater independence and self-sufficiency, and lead healthy lives as valued community members.

Top Photo: Parents at Transition Bootcamp Conference
Bottom Photo: Professionals at Transition Bootcamp Conference



"I am so grateful you are in our community! What we're able to experience and learn through the UCCEDD is invaluable."
Parent attendee



"This event is the single most important professional learning opportunity to increase collaboration, creativity and areas of weakness for transition improvement."
Professional attendee

Research



LEND trainees at poster presentation



CAC members at the AUCD Conference

- This year UCCEDD and affiliated faculty members published **49 peer reviewed journal articles and book chapters** on topics such as
 - Racial disparity in contributions to mortality among youth with Down syndrome
 - Measuring health-related quality of life factors among people with developmental disabilities
- Our Cincinnati LEND trainees were involved and presented on **6 research projects** including
 - increasing food preferences for picky eaters with ASD
 - increasing knowledge in adult medical providers to work with individuals with developmental disabilities through the development of online module trainings
- UCCEDD/LEND faculty and staff conducted **31 research projects**
- Initiated **regular state policy calls** between DD network parties to strategize advocacy in response to state impact of proposed federal policies
- UCCEDD, LEND and DDBP faculty and staff conducted **74 conference presentations** at national, state and regional levels

Information Dissemination

“As the mother of a child on the Autism Spectrum, I wanted to meet with my Congressman Steve Chabot, but didn’t know how. I was referred to Jane at the UCCEDD/LEND. She coached me through what to expect, what to bring, and how to present myself and my information in the meeting. After talking with her, I felt so prepared, the meeting was a success and I feel more willing to schedule other meetings like this because it went so well.” Tulika



Tulika and Steve Chabot



Professionals at Family Support Conference

- UCCEDD developed **138** new products
- Increased **37%** to **1,205** facebook followers
- Hosted **4** twitter chats on topics such employment and mental health
- Educated policy makers on critical issues such as healthcare and the ABA Act
- Created educational fact sheets on
 - LEND’s impact on lives of children with DD
 - Providing perinatal care for women with DD

The first ever Family Support Conference in Jackson (SE Ohio) attracted over 50 attendees and began a relationship with families and professionals in this underserved part of Ohio

Kara Ayers, Associate Director of the UCCEDD, was invited to and spoke at a White House panel on the civil rights of parents with disabilities

Our staff is represented on

44

advisory groups, taskforces, workgroups, council and boards across the state and country

Mission

UCCEDD is a leader in working with and on behalf of children and adults with disabilities and their families so they can lead the lives they want. UCCEDD accomplishes its mission through education, training, research, impacting on policy, and sharing information.



Vision

All people, including children and adults living with disabilities, and their families, fully participate in society and live healthy, safe, self-determined and productive lives.

Community Advisory Committee (CAC)



Community Advisory Committee Group photo

The CAC helps guide the UCCEDD toward the vision by sharing their perspective and knowledge on disability issues.

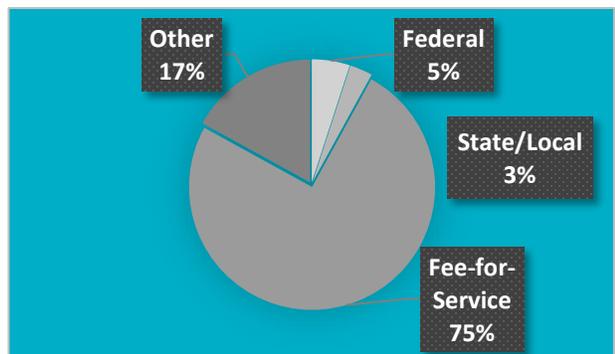
- Actively contributed to the development of the five-year plan
- Participated in focus groups
- Kept abreast on progress of goals and objectives

"I believe that the UCCEDD team absolutely live what they preach, bringing people with disabilities into the organization and the respect that they give to everyone who participates is phenomenal and really is a model." Karen, CAC member



Karen, CAC Member

UCCEDD leveraged \$11 million in grants contracts and other funds



Dollars Leveraged

Each federal \$1 invested in the UCEDDs = \$15 in return on investment