

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

2018-2019 Annual Report

Letter from the Director



Dear Friends and Colleagues, Family Members and Self-Advocates,

I am excited to share our Annual Report for Fiscal Year 2018/19 for the UCCEDD in the Division of Developmental and Behavioral Pediatrics at Cincinnati Children's Hospital with you. It amazes me how quickly a year goes by and how many opportunities we have had to work with you to make Ohio and the nation a better place to live for people with disabilities and their families!

This report provides a snapshot of the work we have completed in the last year to improve the lives of children, adolescents and adults with developmental disabilities and their families.

Most of our work is done in collaboration with community partners, hospital and university colleagues, family members and self-advocates, and we greatly value and appreciate these partnerships. We cannot achieve our goals without all of your work and commitment to people with developmental disabilities, and we are thankful for your support.

FY 18/19 was an exciting and busy year for our UCCEDD and LEND! We had our most diverse LEND cohort ever. We welcomed three graduate students and a Diversity Fellow to work on various community-based projects, including with Refugee Connect to serve refugees with disabilities. We also oriented new Ohio legislators and their staff on the federal and state level about the priorities and needs of the disability community, supported the SABE-led GoVoter project with collecting surveys on the voting experience from voters with disabilities in Ohio, and educated Ohio legislators about the direct support workforce crisis. In addition, we continuously shared information about people with disabilities with thousands of university and hospital colleagues, professionals, family members, self-advocates and policymakers via training sessions, testimony, newsletters, listservs and social media.

In the upcoming FY, we look forward to continuing our work with all of you 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 many thanks,

Interdisciplinary Training



The 2018-2019 LEND Trainee Cohort

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.



Lydia, a LEND social work trainee, talks about her experience with the program. "Learning about Family Centered Care has been instrumental in my role as a CCHMC NICU Social Worker. I often serve as the bridge between families and the medical team, helping each side understand the other, ultimately creating the best medical care scenario for families."

Out of the 109 LEND trainees:

- 24% identified as racially/ethnically diverse
- 23% identified as male
- 14% identified as having a lived experience with disability

Community Education & Collaboration

The UCCEDD conducted **36 continuing education activities and 92 community training activities for 7,787 professionals and 1,768 family members and self-advocates**

on pre-employment skills, addressing challenging behaviors, supporting parents with disabilities and many more topics

Project SCOPE: (Supporting Children of the OPIoid Epidemic)



Drs. Stephanie Weber and Andrea Witwer, LEND Training Directors at UCCEDD and Nisonger Center are working in collaboration with the UCEDD in Wyoming (WIND) on this initiative to identify and train practitioners to screen, monitor and care for children who have been or are suspected of being impacted by opioid use. The team developed an 8-week curriculum and held sessions bi-weekly in spring 2019. Over 50 professionals joined each session and reported satisfaction with the program.



Semhare (pictured left) assisted a local refugee family to learn more about accessible housing options in the community and engage in the IEP process for their children in school.

The UCCEDD conducted 32 Charting the LifeCourse (CTLC) Trainings for 514 individuals. CTLC Trainings have grown over the last year, specifically in cultivating ambassadors who are teaching others on a local and national level, each with a focus on different age groups.



"The CTLC Framework has given my son, who is non-verbal, a voice. I used to just make decisions for him. Now, he has input in where he goes and what he does and enjoys experiences like never before."

CTLC Parent Attendee

LIFT - Smoking Cessation Train the Trainer Classes

This year, the UCCEDD conducted 13 LIFT (Living Independent from Tobacco) Classes to teach individuals with disabilities how to reduce and/or stop smoking. Immediately after the LIFT intervention, CO levels significantly decreased, indicating that smoking had reduced. This decrease was also seen in the one-month follow up with participants.



Individuals who participated in the LIFT course (pictured left)



"I liked the community aspect of the class. I would often see people outside of class and we would ask each other about how quitting smoking was going. Everyone was very supportive of each other." Attendee

Research

- UCCEDD and DDBP faculty members published **40 peer reviewed journal articles and book chapters** on topics such as: Medical interventions for ADHD, Independent living skills in youth with Autism and Smoking cessation efforts in adults with disabilities
- Cincinnati LEND trainees were involved and presented on **8 research projects** including: Diagnoses and interventions related to auditory processing disorder and parent/provider perceptions and Parental impressions of genetic services for individuals with Treacher Collins Syndrome
- UCCEDD/LEND faculty and staff conducted **16 research projects**
- **6 individuals** with developmental disabilities and family members actively participated in the planning and development of research activities
- UCCEDD, LEND and DDBP faculty and staff conducted **36 poster presentations and 11 web based activities** on the local, regional, state and national levels



Winners of the UC/Nisonger LEND Poster Competition



LEND trainees presenting their poster on the observation tool

Amie Duncan, PhD, Assistant Professor, DDBP (pictured right) saw a need to increase daily living skills and executive functioning in teens with autism. She partnered with the University of Cincinnati's Transition Access Program (TAP) to teach their students the daily living skills curriculum she developed and led a LEND team in crafting an observation tool to use with the curriculum (their project pictured left). The observation tool allowed LEND students to work with TAP students in their dorm rooms to see how the curriculum was actually working.



Amie Duncan, PhD, Assistant Professor, DDBP

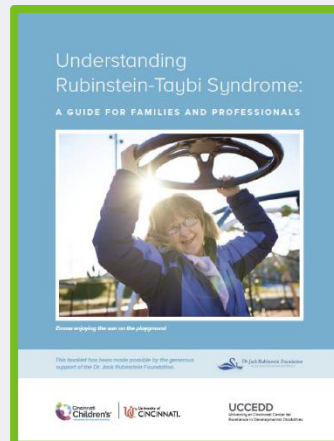
Information Dissemination



Our F2F Team educated Senator Brown on our work to assist families of children and youth with special healthcare needs

- Developed **148 new products**
- Facebook: followers **up 8%**, likes **up 6%**, impressions **up 29%**
- Policy staff met with **13 different state and federal legislators** on disability issues
- Submitted public comment on at least **4 issues** such as:
 - Airline access for people with disabilities
 - Sub-minimum wage
- **Co-hosted twitter chats** on disability issues

The UCCEDD published two pieces related to Rubinstein-Taybi Syndrome, a rare genetic syndrome, for which not much information exists: the "Understanding Rubinstein-Taybi Syndrome: A Guide for Families and Professionals" Booklet and "Rubinstein-Taybi Syndrome: At a Glance", a fact sheet for professionals (pictured below).



Our staff is represented on **40** advisory groups, taskforces, workgroups, council and boards across the state and country

Community Advisory Committee (CAC)



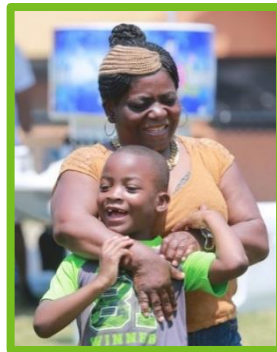
Community Advisory Committee group photo

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.



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



“As a member of the CAC, I’ve been inspired, encouraged and included on projects. I provide care for my grandchildren and have a disability, so transportation is critical for me. I recently experienced an issue with transportation and because of what I’ve learned as part of the CAC, I was able to contact the UCCEDD and Disability Rights Ohio to help me get it resolved.”
Angela Taylor (pictured left with grandson)

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.

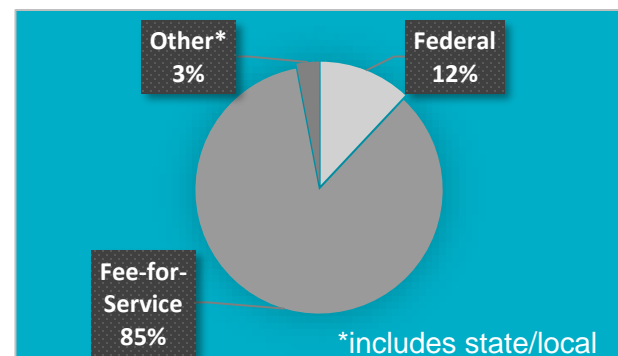
“The CAC provides an essential platform for bringing people to the table to create meaningful discussions about policies impacting people with disabilities, such as the direct service provider crisis. Together, self-advocates, family members, and professionals identified the critical aspects of this problem and developed creative ideas for solutions.”
Kerstin, DD Network Partner and CAC member (pictured right)



Dollars Leveraged

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

UCCEDD leveraged \$7,143,351 in grants, contracts and other funds



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