

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

2017-2018 Annual Report

Letter from the Director



Dear Friends and Colleagues,

I am happy to share with you our Annual Report for Fiscal Year 2017/18 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. 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 FY 17/18, we launched our babysitter training for high-school and college-age students to provide quality care to children and youth with disabilities when babysitting. In collaboration with our LEND program and many community partners, we expanded community programs and events in the Greater Cincinnati area to be fully inclusive and accessible to children and adults with developmental disabilities.

In partnership with the School of Social Work at the University of Cincinnati, we launched the undergraduate Certificate in Developmental Disabilities in the fall 2017, which was met with great interest by students from various disciplines.

We have been active in informing local, regional, state and national policy work, expanded or launched research in the areas of Autism, Down Syndrome and children who are deaf or hard-of-hearing, and have shared products and information with thousands of university and hospital colleagues, professionals, family members, self-advocates and policymakers.

Thank you for the support you have provided 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 gratitude,

Interdisciplinary Training



The 2017-2018 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.

"I benefitted from learning about different diseases/conditions/diagnoses as well as the hands-on experience of volunteering in the community and observing different disciplines."
LEND family trainee

Out of the 89 2017-2018 LEND trainees:
24% identified as racially/ethnically diverse
20% identified as male
30% identified as having a lived experience with disability

"As a result of the LEND program, my presentation and research skills have improved; my awareness of advocacy has increased; and I value self-reflection as a means to understand personal values, actions and beliefs."
LEND professional trainee

Community Education & Collaboration

The UCCEDD conducted

90

community education activities for

5,044

family members and caregivers, self-advocates, professionals and students on Charting the LifeCourse, toilet training, healthcare transition, addressing challenging behaviors and many more

The **Babysitter Training Course** was developed to equip high school and college aged students with the tools to care for kids and youth with disabilities. **30+ students** have completed the course so far.



Course attendees providing care

The Certificate of Developmental Disabilities Program

included **16 students** representing **3 disciplines**

The UCCEDD Director and Associate Director served as guest lecturers for at least 5 lectures, as well as facilitated many other local subject matter experts to participate in the course.

"I have a sibling with a disability and thought I knew all there was to know. It turns out that's not true. This course taught me about all sorts of disabilities, as well as what it looks like to actually get a job."

Training Course Graduate

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 monthly 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 **Columbus** area, as well as **Delaware and Portage Counties** in Ohio, with a great response from family members. These transition trainings allow family members of individuals with developmental disabilities to support their loved ones in gaining greater independence and self-sufficiency, and lead healthy lives as valued community members.



Transition Panel, parents and self-advocate

"You need all the information you can get to navigate transition. Knowledge is the tool to open your future. Grab every piece you can get your hands on."

Attendee

Research



LEND trainees at poster presentation



Jason's Family celebrating World RTS Day

- UCCEDD and DDBP faculty members published **40 peer reviewed journal articles and book chapters** on topics such as:
 - Language performance in young children who are deaf or hard-of-hearing
 - Pediatric and adult nutrition in chronic diseases, developmental disabilities, and hereditary metabolic disorders
- Cincinnati LEND trainees were involved and presented on **6 research projects** including:
 - The impact of the opioid crisis on young children
 - Working to create more inclusive community programming for children with DD and their families
- UCCEDD/LEND faculty and staff conducted **24 research projects**
- **9 individuals** with developmental disabilities actively participated in research activities
- UCCEDD, LEND and DDBP faculty and staff conducted **69 presentations** on the local, regional, state and national levels

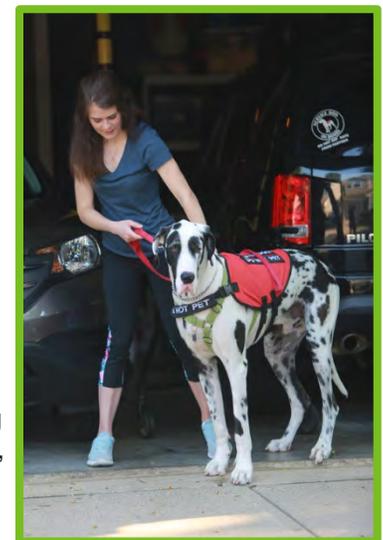
"The UCCEDD informs the public of new and on-going issues, activities and events regarding disabilities. They are at the forefront of providing lots of new information. UCCEDD offers classes/updates for parents which allows them contact with other parents to build supports. This is wonderful."

Parent

Information Dissemination

The UCCEDD partnered with the Nisonger Center to provide an innovative model of **Smoking Cessation** for people with disabilities using the LIFT curriculum (Living Independent from Tobacco).

- Developed **73** new products
- Facebook: followers up 10%, engagement up 19%, message volume up 43%
- Policy staff met with **15** different state legislators; strengthened relationship with Senators
- Created policy briefs on
 - Making Accessible Taxis an Option in Ohio
 - Ending Organ Transplant Discrimination on the Basis of Disability
- Co-hosted 2 podcasts on parenting with a disability



Caroline getting her service dog, Clark, ready for their walk

Our staff is represented on

44

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

Community Advisory Committee (CAC)



Community Advisory Committee group photo

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

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.



One three-year CAC member owns a successful disability advocacy consulting business. She serves on multiple boards and coalitions around issues such as identifying more affordable, accessible transportation and housing options for people with disabilities.

"The UCCEDD helps people with disabilities interact and get comfortable with the community and they help people in the community get comfortable with us."
Heather, CAC member

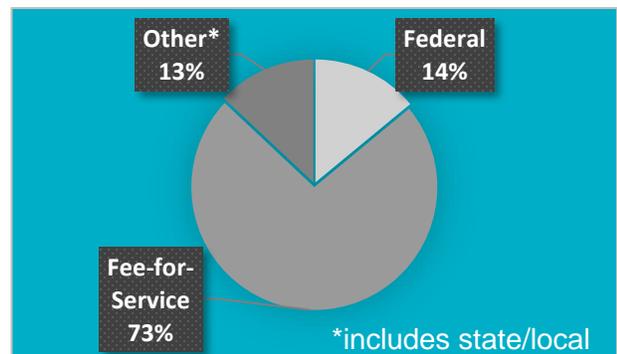


Heather, CAC Member

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.

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



Dollars Leveraged

Each federal \$1 invested in the UCCEDD = \$20 in return on investment