

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

2019-2020 Annual Report

Letter from the Director



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

I am excited to share the University of Cincinnati UCEDD Annual Report for Fiscal Year 2019/20 with you. We are one of 67 University Centers for Excellence in Developmental Disabilities (UCEDDs) and are located in the Division of Developmental and Behavioral Pediatrics at Cincinnati Children's Hospital. We cannot achieve our goals without all of your work and commitment to people with developmental disabilities, and we are thankful for your support.

This FY, we have all encountered national and global challenges, with the COVID-19 pandemic, racial tension and injustice being just a few of them. Many people with disabilities and their families have been directly impacted by these challenges. However, despite our new normal, we were able to adjust and provide support and information to people with disabilities, their families and professionals, partner with community organization, continue our research and educate students and professionals in the community. We have seen great strength, flexibility and adaptability in our communities, and are encouraged by the resilience of everyone with whom we work.

This report highlights various projects and activities that we have worked on in fiscal year 19/20. Prior to COVID-19, our in-person activities included things such as: sensory-friendly community engagement events at venues like the Cincinnati Art Museum; LEND group discussions and presentations; Family Navigation Workshops; and research conversations on Early Intervention. Despite COVID-19, we continued to share 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. We hope that you will enjoy reading about our work and partnerships this year.

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.

Interdisciplinary Training



The 2019-2020 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.



Arin, a LEND community engagement trainee, talks about her experience with the program. "My eyes were opened to see how non-accessible many of our systems and communities are. I am now more educated and motivated to be part of the change toward individualizing systems to include the unique differences of all individuals and to be truly accessible."

Out of the 92 LEND trainees:

- 27% represented a diverse background
- 19% identified as male
- 15% identified as having a lived experience with disability

In service to you,

Community Education & Collaboration

The UCCEDD conducted **44 continuing education activities and 124 community training activities for 7,970 professionals and 2,101 family members and self-advocates** on promoting positive behaviors during COVID-19, preparing for an emergency, learning how to care for yourself as you care for others and many more topics

Rubinstein-Taybi Syndrome (RTS) Online Learning Modules

We developed 10 video modules on RTS, nine of which focused on medical subspecialty care for patients with RTS and one is dedicated to families' experiences of living a good life with RTS in their homes, schools and communities. We hope these videos will contribute to increased understanding and optimal treatment of individuals with RTS. [All videos can be found here.](#)



Center for Dignity in Healthcare for People with Disabilities

A national coalition to identify and reduce life-limiting healthcare inequities for people with intellectual and developmental disabilities by improving access to medical protocols that reduce medical discrimination. The Center created two fact sheets related to COVID-19. [One for healthcare professionals](#), and [one for people with disabilities and their families](#).

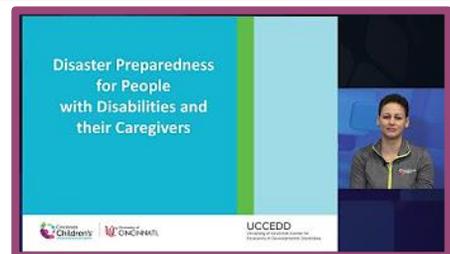


Training Success Despite Going From Physical to Virtual

All of our trainings went from physical to virtual in March, but we utilized COVID-19 to strengthen relationships and to continue to provide education and support. One session was especially popular, "Extended School Year and Compensatory Services During and After COVID-19". One parent had this to say, "As soon as I got off the webinar I emailed the supervisor of the special needs program and plan to set up a call with the team soon to discuss metrics and tracking of progress."

Disaster Preparedness Videos for People with Disabilities and their Caregivers

These two videos discuss how to prepare for the 10 Impact Areas of Disasters, create an Emergency Plan with the assistance of a caregiver, and understand the necessary steps for sheltering in place, community sheltering, and evacuating. One video shows how a self-advocate and his caregiver have discussed what to do in the event of an emergency. The videos can be found [here](#).



Research

- UCCEDD and DDBP faculty members published **53 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 **6 research projects** including: Snack Time Intervention for Children with ASD and Access to Inclusion: Developing Professional Standards for Community Settings
- UCCEDD/LEND faculty and staff conducted **12 research projects**
- **17 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 **29 poster presentations and 14 web based activities** on the local, regional, state and national levels

**Published
30% more
than last
year**



TALI Project Newsletter

TALI Project

The Technology Assisted Language Intervention (TALI) Study is designed to improve the language skills of children who are deaf/hard of hearing with a range of cognitive, developmental and communication needs, by using augmentative and alternate communication technology as a teaching tool during speech-language therapy sessions. “We believe that this project will have a positive impact on children and their families by enhancing a child’s language ability, facilitating not only communication, but also social relationships,” says Jareen Meinzen-Derr, PhD, MPH, FACE, lead investigator on the study.

Information Dissemination



LEND students meet with policy makers at DD Advocacy Day

- Developed **197 new products**
- Facebook followers **up 18%**
- Policy staff met with **15 different state and federal legislators** on disability issues
- Submitted public comment on at least **6 issues** such as:
 - Health Equity
 - Home and Community Based Services
- **Co-hosted twitter chats** on disability issues

Support During COVID-19

Much of our focus since March has been on COVID-19 and how to support people with disabilities during this pandemic. For example, we have created a number of social stories to help children with disabilities learn about mask wearing, social distancing, going to school, etc. Learn more here: www.uccedd.org/covid-19-info



The “I Can Wear a Mask” Social Story has been viewed over 5,000 times on YouTube

Our staff is represented on

45

advisory groups, taskforces, workgroups, councils 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.

“Participating in the CAC for the allows me to learn from staff, as well as other local disability advocates and service providers, about current research, legislation, and education programs that benefit people living with intellectual and developmental disabilities. I often share the information, resources, and opportunities with our constituents with spina bifida.” Diane, CAC member (pictured left)



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.

“We must always remain tireless, and forever vigilant, in our efforts to advocate for people with disabilities. In the face of adversity and blatant discrimination against people with disabilities, with relation to medical rationing, etc., we have to be united more than ever before.”

Michael, CAC member (pictured right), on why he joined the CAC



Dollars Leveraged

Each federal \$1 invested in the UCEDDs = \$14 in return on investment

UCCEDD leveraged \$7,967,388 in grants, contracts and other funds

