

UCCEDD ANNUAL REPORT 2020-2021



LETTER FROM THE DIRECTOR



Dear Friends and Colleagues,

I am excited to share the University of Cincinnati UCEDD Annual Report for Fiscal Year 2020/21 with you. We are one of 67 University Centers for Excellence in 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. Our affiliations and partnerships are always making us a better UCEDD, and we love to see what we can do together.

We never dreamed that fiscal year 2020/21 would have looked like it did, specifically related to the COVID-19 pandemic, but we have been able to serve a broader audience due to the virtual nature of the world. We have learned so much more about accessibility and are making strides every day to ensure that the products and communications we develop are accessible and inclusive.

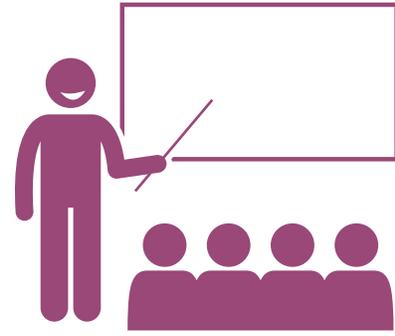
This report highlights just a few of our projects and activities that we have worked on in fiscal year 2020/21. Our UCEDD engaged in multiple opportunities to increase our cultural humility. We developed a three-part virtual training series for families who have children and youth with special healthcare needs on dealing with everyday fears of COVID-19, how to creatively plan summer activities and how to handle school conversations in the fall of 2020. We have continued to increase our connections with disability agencies as well as grassroots organization and the community.

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.

In Service To You,

A handwritten signature in blue ink, appearing to read "J. Keen".

INTERDISCIPLINARY TRAINING



LEADERSHIP EDUCATION IN NEURODEVELOPMENTAL DISABILITIES (LEND) TRAINING PROGRAM

OUR CINCINNATI LEND PROGRAM DID AN AMAZING JOB MOVING FROM 100% IN PERSON TO 100% VIRTUAL ALMOST OVERNIGHT. THEY THRIVED IN LEADING AND PARTICIPATING IN A NUMBER OF VIRTUAL OUTREACH CLASSES, SUCH AS COLLABORATING WITH A CHILD'S SCHOOL TEAM THROUGH COVID-19, AND HOW TO USE CALMING STRATEGIES IN THE COVID-19 STORM.

OUT OF THE 29 LONG TERM TRAINEES:



IDENTIFIED AS ETHNICALLY
DIVERSE

&



IDENTIFIED AS HAVING A
PERSONAL RELATIONSHIP
WITH DISABILITY

INTERDISCIPLINARY TRAINING



Photo of LEND FY 20/21 class

“I enjoyed being part of the LEND program immensely. It is a wonderful opportunity to create leadership skills to take into society and utilize them to better the community for people with disabilities.” LEND Family Trainee

COMMUNITY EDUCATION AND COLLABORATION

- 42 Continuing Education Activities
- 58 Community Education Activities
- 2,622 Professionals and 1,089 Family Members Trained on Addressing Behavior Challenges at Home During COVID-19, Toilet Training, Extended School Year and Compensatory Education Services During the COVID-19 Pandemic, and many more topics.



COMMUNITY EDUCATION + COLLABORATION

VACCINE PRIORITIZATION DASHBOARD



The Center for Dignity in Healthcare launched a first-of-its kind dashboard to track the priority groups status' developed to determine vaccine eligibility for different groups, including people with disabilities. Visit the dashboard [here](#).

"INTELLIGENT LIVES" FILM SHOWING

We organized two showings of the film with over 280 people attending, featuring a panel discussion with self-advocates, parents, employers, and faculty members.

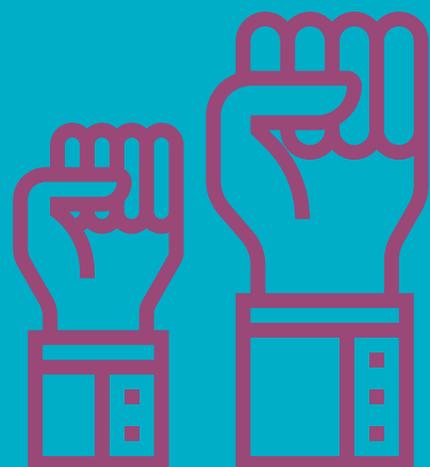


RESEARCH

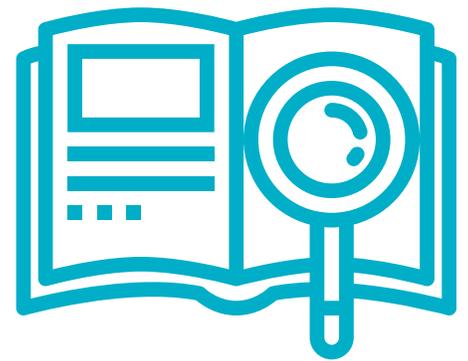
UCCEDD and DDBP faculty members published 44 peer reviewed journal articles and book chapters on topics such as: Raising Awareness of Disabled Lives and Health Care Rationing During the COVID-19 Pandemic, and No Body is Expendable: Medical Rationing and Disability Justice During the COVID-19 Pandemic.

UCCEDD/LEND faculty and staff were involved in 21 research projects including: supporting parents of young children with ID/DD who have behavior challenges and want guidance in how to address these challenges, and a study aimed to measure healthcare access for refugee families that included a member with a disability.

17 individuals with developmental disabilities and family members actively participated in the planning and development of research activities.



RESEARCH SPOTLIGHT



COVID-19 Vaccine Prioritization

UCCEDD Associate Director, Kara Ayers, collaborated on an article outlining the importance of providing accurate and accessible information about the COVID-19 vaccine to people with disabilities. The article, published in *The Lancet*, discussed how people with disabilities have been excluded from COVID-19 response efforts. Considering that each state is responsible for vaccination efforts, there is a gap in accessibility standards between each state website. John Hopkins Disability Health Research Center and the Center for Dignity in Healthcare for People with Disabilities created a COVID-19 Vaccine Prioritization Dashboard for People with Disabilities. This dashboard compiles useful information from all 50 states and presents information in an accessible format.

INFORMATION DISEMINATION

WHITE HOUSE PRESENTATION

On April 9, Dr. Kara Ayers addressed the Biden White House COVID-19 Equity Task Force to discuss how the disability community's needs could better be met through vaccination.



TELEHEALTH PROJECT



With funding from Family Voices, we were able to present webinars on telehealth for Ohio families in English and Spanish. We also created telehealth fact sheets in English, Spanish, and Somali.

INFORMATION DISSEMINATION

- Developed 142 new products
- Facebook followers up 9% at 1,919 followers
- Policy staff met with 28 state senators and representatives to discuss the impact of pending legislation on Ohio's citizens with disabilities
- Submitted public comments on issues such as: airline travel, COVID-related funding for the Ohio Department of Special Education, and enforcing public health recommendations related to disproportionate impact on people with disabilities



COMMUNITY ADVISORY COMMITTEE (CAC)



Photo taken prior to COVID-19 pandemic

The CAC guides the UCCEDD by helping to create the vision and and move toward it. The 25 members of the CAC met four times virtually this year to give their ideas for how the UCCEDD can help people with disabilities and their families live the lives they want.

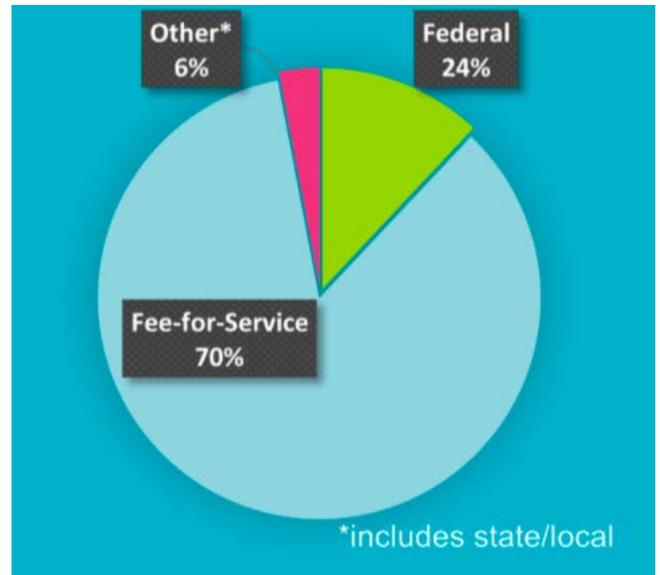
CAC MEMBER SPOTLIGHT



As a member of the CAC, Louis Friedman has learned that the work of advocacy in and for people with disabilities is critical for improving lives. He has learned what kind of focus and dedication is required to make positive changes.

DOLLARS LEVERAGED

- The Division of Developmental and Behavior Pediatrics at Cincinnati Children's Hospital and our UCCEDD, as part of DDBP, leveraged \$7,293,522 in grants, contracts, and other funds
- Each federal \$1 investment in the UCCEDD = \$14 return on investment



Core Team

Ilka Riddle, PhD; Kara Ayers, PhD; Jen Smith, PsyD, BCBA-D; Steph Weber, PsyD, MPH; Amy Clawson; Erica Coleman; Marion Cosgrove Rauch; Anna Ficker; Lynne Fogel; Jane Gerhardt; Vicki Hennessy; Rachel Miller; Sarah Phillips; Celia Schloemer; Leah Smith; Laura Srivorakiat; Molly Sawyer; Elizabeth Trenkamp; Jennifer Walsh; and Catie Woods.



The Ohio Family 2 Family staff meeting on zoom with the Family Caregiver Professional Advisory Council