

UCCEDD/LEND NEWSLETTER Summer 2019



Rafey and his mom, Hadia taking a selfie

Charting the LifeCourse Parent Testimonial

Hadia attended one of our **Charting the LifeCourse (CTLIC) trainings** and had this to say about how it has impacted her family's life. "This training helped me to realize that it's not all about me, but it is about what he (Rafey) wants. He is nonverbal, but he was telling us he wanted

Welcome New CAC Members



Photo of 2019/2020 CAC Members

July marks the beginning of the new UCCEDD Community Advisory Committee year. We are pleased to welcome our new Chair, Louis Friedman; Vice Chair, Diane Burns; and new members: Michael Denlinger, Self Advocate, Member of Housing Network of Cincinnati and DD Council Member; Rob Festenstein, Center for Independent Living Options; Essie Peterson, SABE Advisor, GoVoter Project; Kevin Potts, Ken Anderson Alliance; and Jena Wells, Down Syndrome Association of Greater Cincinnati

more independence and the CTLC framework has given him a voice. Prior to this, I simply made decisions for him, now I ask more questions. And because of this, he is now asking more questions. He will ask about his day. Where are we going? To a restaurant? What restaurant? Then he'll google the restaurant and we will look at the menu. He feels more prepared and it has reduced his anxiety, so he has a better experience."

[Read more of their story here](#)

Down Syndrome Research Studies

There are three different research studies related to Down Syndrome, looking for participation: Children 2.5 to 7 Years Old, Children and Teens 6 to 17, Children 6 to 17 Years Old and Their Parent

[Details Here](#)

Supporting Families of Children and Youth with Special Healthcare Needs (CYSHCN) whose Nursing Services have been denied

Ohio Family 2 Family's goal is to educate and advocate for nursing care solutions and policy changes that sustain and/or improve the health and safety of children and adults with intensive medical needs and developmental disabilities.

[More about solutions and resources](#)

Early Matters. We are excited to see what this year brings!

Success with the LIFT (Living Independent From Tobacco) Program



Photo of LIFT participants

The purpose of LIFT is 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. One participant had this to say about the course, "I liked the community aspect. 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."

Policy Paper Published, "Fostering Disability Advocates: A Framework for Training Future Leaders"



Transition Bootcamp Conference to Resume in 2020

Our Transition Bootcamp Committee has decided to take a year to evaluate the impact that the conference has had up to this point and to make sure we are serving families with transition age kids to the best of our ability. That being said, we will not host a traditional Transition Bootcamp Conference in the fall of 2019, but will resume in the fall of 2020. Thank you for all that you do to make this event a success and we look forward to bringing an updated conference in 2020.

Through Interprofessional Education"

Stephanie Weber, Jennifer Smith, Kara Ayers and Jane Gerhardt collaborated on this policy paper aimed at teaching policy and advocacy skills specific to the underserved population of individuals with developmental disabilities.

[Read more here](#)

Upcoming Events

Monday, September 16, 9:30am - 11:30am - Care Connections: Understanding DDBP & Community Support Options, \$10 per family

Thursday, October 17, 6pm - 8:30pm - Northeast Ohio Regional Transition Collaborative

Wednesday, October 23, 5:30pm - 7:30pm - Managing Anxiety: Helping Kids with Developmental Disabilities Cope and Succeed, \$10 per family

Tuesday, November 5 & Tuesday, November 12, 9am - 12pm - Toilet Training for Children with Developmental Disabilities, \$25 per family

Monday, November 18, 9:30am - 11:30am - Understanding Behavior in Individuals with Developmental Disabilities, \$10 per family

Monday, December 9, 5:30pm - 7:30pm - Care Connections: Understanding DDBP & Community Support Options, \$10 per family

Details about all trainings and events, including Transition Booster sessions can be found [here](#)

**University of Cincinnati Center for Excellence in
Developmental Disabilities**
3430 Burnet Ave., MLC 4002 Cincinnati, OH 45229
www.uccedd.org

Connect with us

