

**HDI Consumer Advisory Council
Online meeting via Zoom
Monday, September 14, 2020 10:30am – 1:30pm**

In attendance today... CAC Members

Vivian Lasley
Skylar Koehler
Morgan Crawford
Cathy Lerza
Jennifer Hicks
Carrie Stith-Webster
Kathy Sheppard-Jones
Camille Collins
Lee Gordon
Walt Bower
Joe Cowan
Meghan Ackerman
Emily Moseley

Presenters: Caroline Gooden, Stephanie Meredith

- 1) Welcome & Introductions Vivian Lasley

Vivian Lasley began the meeting. All members introduced themselves.

- 2) Review & Approval of June Minutes Vivian Lasley

The CAC members reviewed the June minutes. Jennifer Hicks moved to accept the minutes and Joe Cowan seconded. The motion passed and the minutes were accepted.

- 3) AUCD update – Council on Leadership in Advocacy (COLA) Sherece Cole

Walt Bower provided a COLA update. The previous COLA meeting discussed guardianship and voting, intellectual disability affecting one's ability to vote, and voting challenges, such as transportation and safety, due to COVID-19. Voting by mail was also discussed. In Kentucky, a voter can request an absentee ballot at govoteky.com until October 5, 2020.

- 4) You Can Do So Many Things! Kathy Sheppard-Jones

Kathy Sheppard-Jones welcomed and thanked all the members of the CAC for their service. She emphasized the importance of the CAC by saying that working together allows us to do meaningful work. Kathy has written a book called *You Can Do So Many Things!* The book is available on HDI's website as an accessible pdf download at hdi.uky.edu/ecbook and there is an online audio version. It is also available in a hard and softcover. The idea of the book was for

kids around the ages of 4-6 to think about their future careers. The book follows Flynn as she visits different sites around Kentucky that have a connection to horses. Flynn learns about the different types of careers one can have in the horse industry. Brittany Granville did the illustrations and Caroline Gooden edited the book. The book encourages thinking about employment and what work means for all people.

The book launched in August. Initially, 1000 books were printed and childcare providers in Kentucky received 750 of the books. The next step is to make an AAC version. There has been excellent feedback from families, kids, educational providers, and the Kentucky Equine Education program. The book has been entered into the Equine Literacy Fair and Competition.

Kathy asked for suggestions of places, spaces, and thoughts on who needs the book. Feedback from the CAC members included: Vocational Rehabilitation, Head Start, Prescribed Pediatric Extended Care (PPEC) at Redwood, Equine Pet Therapy, and the Kentucky Equine Humane Society. Lee Gordon said that he would send the book to staff and that he appreciates the audio component. Lee also mentioned 4H and the Future Farmers of America. He suggested that giving them the book may prompt them to consider their role in including kids with disabilities. Kathy said the discussion was helpful, and she will keep the CAC posted.

Kathy also participated in an AUCD webinar focused on the topic of council engagement. She came away with a new idea for a future CAC meeting involving a pitch contest, where HDI projects provide a two-minute overview of their project, and CAC members determine a winner. The format is a good way for everyone to learn about projects at HDI.

5) National Center for Prenatal and Postnatal Resources project update Stephanie Meredith

The National Center for Prenatal and Postnatal Resources creates material for parents who have received a diagnosis for their child. It provides training for providers about the social model of disabilities. A CAC member asked if they are doing any research into COVID and isolation. Stephanie responded that COVID had caused things to shift. For example, in-person presentations with medical professionals and parents went online. Due to COVID, people have been creative. For instance, local organizations are hosting new parent zoom gatherings.

A CAC member asked if there is any outreach that discusses trauma-informed care and person-first language. Stephanie replied that it is typically included in best practices. Stephanie also discussed a journal article describing the stories of 300 women who received a Down syndrome diagnosis for their child. For 80% of the women in the study, this was a flashbulb memory, described as a memory that endures for years. A CAC member commented that the article could be a support for parents and siblings.

Stephanie then provided the CAC with an overview of Lettercase. It seeks to resolve the disconnect between physicians' desire to do well while addressing their lack of language. Lettercase has free digital resources on the website at www.lettercase.org, and the Lettercase app is available on the App store. Lettercase is directed to physicians, but

understandingdownsyndrome.org is for new families. The books are available for free online as pdf downloads. The books are updated every five years to keep current with new information.

6) Project SCOPE update Caroline Gooden

Caroline Gooden provided a Project SCOPE update. Project SCOPE (Supporting Children of the Opioid Epidemic) is based on the ECHO (Extension of Community Health Outcomes network) training model. The purpose of the training is to build the capacity of providers serving children birth to five years old with Neonatal Abstinence Syndrome (NAS) and other substance use disorders with their families.

There are three cohorts (2020, 2021, 2022) in the trainings and the trainings will happen each fall. The Kentucky team members are Kathy Sheppard-Jones, Caroline Gooden, Brandon Cannada, Christine Hausman, and Emily Moseley. The training participants include Pathways staff, childcare staff and consultants, early childhood mental health specialists, early interventionists, pediatricians, nurses, PTs, OTs, and peer supports.

There are seven zoom calls, presenters, facilitators, co-facilitators with lived experience, and 80 participants. The curriculum focuses on topics related to NAS infant and family care, including: the social determinants of health, NAS, addiction and treatment, having difficult conversations, monitoring child development, trauma and its effects, and the role of peers for families in recovery. The sessions include an introductory presentation by a state expert on the topic, following by guided discussion of a current practice dilemma geared toward the specific needs of Kentucky providers.

There has been overwhelming support in Kentucky for this program. A CAC member asked if there is any work happening within the court system. Caroline replied that people from DBH work with the court system by helping to create reunification plans for families. One CAC member commented that the court systems need support and suggested targeting groups such as judges and Kentucky fiscal courts. Another CAC member asked about including parole officers. Caroline added that for the next training, they would investigate new partners.

7) 2020 Kevin Burberry Award Emily Moseley

Emily Moseley described the Kevin Burberry Award. HDI presents this award to a student affiliated with HDI via the Graduate Certificate, Research Assistantship, practicum student, or other significant Institute involvement. The student has demonstrated a strong commitment to people with disabilities through university and community projects and experiences, has demonstrated the leadership qualities exemplified by Kevin's own life; and has shown a commitment to academic excellence in his or her chosen field of endeavor as indicated by course achievements, presentations or publications. Emily Moseley was presented with the award this year. She humbly accepted the award with gratitude and is incredibly honored. Emily sees Kevin Burberry as a role model and a guiding light in her work.

8) Agency Updates (P & A, DD Council, DDID Each Agency
OCSHN, OVR)

Protection & Advocacy – Camille Collins reported they are continuing to monitor facilities. They have monitored 140 facilities virtually for possible abuse and neglect. These facilities include SCL programs, TBI programs, nursing facilities, in-patient psychiatric hospitals, and jails. Camille also reported that they are working on voting PSAs with HDI, including how to request a ballot, how to complete a ballot, registering to vote, signature compliance on the ballot, mailing the ballot, and tracking the ballot. They continue to communicate with a group of stakeholders, including HDI, CCDD, doctors, and individuals with disabilities to ensure ventilators are not reallocated for another person when they go into a hospital setting. P&A has been writing to the Cabinet of Health and Family Services asking that supports be increased to two people per patient and that triage teams have disability awareness training.

Division of Developmental and Intellectual Disabilities - Cathy Lerza reported the Medicaid Waiver Management Application (MWMA), a statewide online system, was implemented in 2015 for providers and state staff to coordinate the activities of the Medicaid waivers. The waivers relevant to this group are the Michelle P waiver and the Supports for Community waiver, commonly known as the SCL waiver. Initially just case management staff were able to use it, but Medicaid will open it for all service providers to use so that providers can submit incident reports, making it much more efficient to track and trend incidents. DDID has been keeping Medicaid providers updated on the pandemic, following the guidance from both the CDC and Kentucky. Since March, DDID has been compiling resources related to COVID-19 and sending them to providers. DDID requested providers to complete several surveys recently, including a survey on staff stability, a survey focusing on employment, and a general comprehensive annual survey. The annual survey includes sections on: technical assistance received and desired from DDID, person-centered planning, services to people who are deaf, hard of hearing, or have a combined hearing and vision loss, autism, human rights and behavior intervention, quality improvement, and pandemic concerns.

Office for Children with Special Health Care Needs - Lee Gordon reported virtual clinics have transitioned back into face to face clinics after staff received personal protective equipment (PPE). The Family to Family grant is continuing to connect parents with resources.

9) New Business and Announcements

Vivian Lasley

Walt announced the upcoming Accessible Transportation HDI Seminar scheduled for Friday, September 18, from 1-3 p.m. The seminar will be fully online. The presenters are Arthur Campbell Jr., Frank Huffman, and Maria Kemplin.

Cathy Lerza made a motion to adjourn the meeting and Joe Cowan seconded. The meeting adjourned at 1:24 pm.

NEXT CAC MEETING: Monday, December 7, 2020 at 10:30 AM – 1:30 PM. The next meeting will be a virtual meeting.