

**HDI Consumer Advisory Council
Online meeting in Zoom
Monday June 6, 2022 10:30AM – 1:30PM**

In attendance today... CAC Members

Meghan Ackerman

Skylar Koehler

Vivian Lasley

Cathy Lerza

Joe Cowan

Julie Pfeiffer

Jonathan White

Walt Bower

Carrie Stith-Webster

Jennifer Hicks

Presenters: Maria Kemplin, Harold Kleinert, Teresa Belluscio, Stephanie Meredith

1) Welcome & Introductions Joe Cowan

Joe Cowan opened the meeting. All members introduced themselves.

2) Review and Approval of March minutes Joe Cowan

Joe asked for members to review the March minutes. Cathy requested a correction to the minutes and Julie noted the correction. Joe made a motion to approve the minutes with the necessary correction, and Skylar seconded.

3) AUCD update – Council on Leadership in Walt Bower
Advocacy (COLA)

Walt highlighted the work of COLA. The purpose of COLA is to enhance the Association of University Centers on Disabilities (AUCD) by fostering current and new leaders with lived experience of disability, including their family members, to promote leadership in their programs and communities. In addition, the Council on Leadership and Advocacy helps the AUCD association to develop leaders and mentors that build the capacity of the network to affect change at the local, state, and national levels. The membership of COLA is made up of individuals with

disabilities and family members from each network member across the AUCD network. COLA members are involved in Consumer Advisory Councils at UCEDDs.

- 4) Transportation Initiative update Maria Kemplin
-Input and feedback from CAC members

Maria Kemplin introduced the Transportation Initiative. The Transportation Initiative aims to increase transportation options and access for Kentuckians with disabilities. Maria shared the Transportation Initiative website (<https://transportation.hdi.uky.org>) that includes videos, audio files, reference cards, and workbooks on a variety of transportation topics. A number of trainings were provided over the last year to special education teachers, paraprofessionals, parent advocacy groups, self-advocate groups, and waiver providers. Maria also provides technical assistance to help people understand the rules and regulations about transportation services and to help individuals and community groups needing assistance. Maria proposed that a group of 4 to 5 individuals with lived experiences of transportation issues share their story at the 2022 AUCD Conference.

- 5) Consumer Advisory Council By-laws update Harold Kleinert
-Input and feedback from CAC members

Harold Kleinert provided an update on the Consumer Advisory Council by-laws as approved by the subcommittee. Subcommittee members included Joe, Skylar, Cathy, and Harold. Revisions include elimination of redundancy and improvements in format clarity. The subcommittee recommended the majority of voting members should consist of people with disabilities and their family members.

To reflect the national Council on Leadership in Advocacy (COLA), the CAC will now have two co-chairs, one self-advocate and one family member. The two co-chairs will serve for three years with the first year of the term as co-chair elect. This change provides for more stability in leadership, shared leadership responsibilities, and a year of leadership preparation. Additionally, the subcommittee recommended an increase in compensation for CAC participation to \$200 per meeting. Voting on the CAC by-law changes will not be held until the next meeting to provide CAC members the opportunity to review a final copy.

- 6) 2022 Summer Leadership Experience Camp Teresa Belluscio
-Input and feedback from CAC members

Teresa provided an update on the 2022 Summer Leadership Experience Camp. The purpose of the Summer Leadership Experience camp is to provide counseling and resources, and to develop skills for the next educational steps (additional training, college, or internships) for high school juniors and seniors with disabilities. The camp is funded by the Kentucky Office of Vocational Rehabilitation (VR). VR counselors and special education high school teachers selected thirteen students to attend this summer's camp. The camp will occur in-person at the University of Kentucky, July 6-9. Speakers this year include Cody Clark, Travis Freeman, and Chris Hammons.

- 7) Patient-Centered Outcomes Research Stephanie Meredith
Institute (PCORI) project
-Input and feedback from CAC members

Stephanie presented updates on the Patient-Centered Outcomes Research Institute (PCORI) Engagement Award project. The mission of the PCORI Engagement Award is to disseminate patient-centered outcomes research results about disabilities to Black and Hispanic new and expectant parents of children with disabilities. The project starts July 1st. Aims of the projects are to build coalitions between patient advocacy leaders, health equity experts, medical professional, and Black and Hispanic parents of children with Down syndrome (DS) to provide input about recommendations for disseminating PCORI findings to new and expectant parents learning about a diagnosis.

The PCORI project award activities include (1) community conversations to identify barriers, determine strategies to overcome barriers, and document recommendations and priorities, (2) meeting with health equity experts to review themes from patient stakeholder meetings, and (3) meeting with national health care experts to construct a plan to better disseminate research into medical practice. Other project priorities are equitable compensation for participants and diverse representation in every stage of the project. Walt asked about questions that will be posed during community conversations and Stephanie reported that the community conversation model will be followed.

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

Division of Developmental and Intellectual Disabilities – Walt reported for Cathy Lerza. Walt discussed that HDI’s online Kentucky Disability Resource Guide is posted on the DDID website through an updated link and demonstrated how to access the online Kentucky Disability Resource Guide. DDID is working with the Kentucky Department for Medicaid Services (DMS) on the renewal of the Supports for Community Living (SCL) waiver. DMS is currently working with the Centers for Medicare & Medicaid Services (CMS) to answer questions about the renewal submitted for the Acquired Brain Injury (ABI) waiver. DMS will proceed with the SCL waiver once they have worked everything out with the ABI waiver.

Office of Vocational Rehabilitation – Jonathan White reported that OVR is currently housed within the Education Cabinet. The Education Cabinet will be merging with the Labor Cabinet on July 1st of this year. OVR will be implementing changes to preemployment transition services, which are provided to students with disabilities. OVR will be participating in the Carl D. Perkins Vocational Training Center Perkins Center graduation ceremony Friday, June 10th.

- 9) Election of New CAC member All

The Nominating Committee presented Shiyla Cruz as a self-advocate for the CAC. Shiyla is a disabled self-advocate with a long history of involvement with the developmental disability community. There was not a quorum present at this point of the meeting so there was a suggestion for a vote via email. The Chair of the CAC agreed to a vote via email.

- 10) New Business and Announcements Joe Cowan

No new business or announcements.

Jonathan made a motion to adjourn the meeting, and Skylar seconded. The meeting adjourned at 1:30pm.

NEXT CAC MEETING: Monday, September 12, 2022 at 10:30 AM – 1:30 PM