HDI Consumer Advisory Council Online meeting in Zoom Monday September 11, 2023 10:30AM – 1:30PM

In attendance today... CAC Members

Skylar Koehler
Jake Cruz
Jonathan White
Walt Bower
Cathy Lerza
Vivian Lasley
Joe Cowan
Camille Collins
Julie Pfeiffer
Meghan Ackerman

Joshua Seigle

Presenters: Kristen Dahl, Haley Potter, Mykal Leslie, Elizabeth Kries

1) Welcome & Introductions

Jake Cruz

Jake opened the meeting. All members introduced themselves.

2) Review and Approval of June Minutes

Jake Cruz

Jake asked for members to review the June minutes. Joe made a motion to approve the minutes, and Joshua seconded. June meeting minutes were approved.

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

Vivian Lasley

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. COLA membership is made up of individuals with disabilities and family members from each network member across the AUCD network. COLA meetings are held quarterly with the next COLA meeting happening inperson at the AUCD 2023 Conference.

4) Association of University Centers on Disabilities (AUCD) 2023 Conference Overview

Vivian Lasley

Vivian provided an overview of the AUCD 2023 Conference. AUCD is a network of interdisciplinary centers working to improve the health, education, and social and economic well-being of persons with disabilities and their caregivers. The conference will be held November 5th through the 8th in Washington, D.C. The theme of this year's conference is "Emerging Leaders: Shaping the Future." Joe Cowan encouraged CAC members to attend if they are interested.

5) Students Supporting Public Health and Disability In Higher Education (Sphere) project
-Input and feedback from CAC members

Kristen Dahl Haley Potter

Haley and Kristen provided an overview of the Sphere project. Haley showed a video introducing the Sphere project. Protection and Advocacy is partnering with HDI on the Sphere project. Sphere is about creating connections related to public health and disability for students in higher education. Sphere works to connect students with resources, each other, and the institute. Four informaticians are creating and sharing resources with students across Kentucky including plain language one-pagers, social media posts, and presentations to classes. Sphere has a Discord channel which allows students across the state of Kentucky to connect with one another to share resources and have discussions. Informaticians are also cultivating relationships between student organizations and HDI. Sphere produces a webinar series that is held on the last Wednesday of every month at 4pm EST.

6) HDI Evaluation update
-Input and feedback from CAC members

Mykal Leslie

Mykal introduced himself and asked for the CAC members to provide a short introduction of themselves. Mykal then provided an update on the HDI evaluation unit. The evaluation unit currently oversees 16 externally funded projects with ongoing relationships with the Kentucky Department of Education, Kentucky Department of Behavioral Health, Developmental and Intellectual Disabilities, and the Office of Vocational Rehabilitation. Mykal highlighted some of the externally funded grants with which the evaluation unit works. The evaluation unit also performs internal evaluations for projects including RETAIN, CORE, SHEP, and CWTP. The current goal of the evaluation unit is to serve HDI as a whole and provide quality technical assistance and training on effective evaluation practices.

Potential future directions for the unit include cross-training opportunities to learn more about evaluation principles and practices, revamping the CORE evaluation, and further collaboration with other units across HDI.

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

Protection and Advocacy - Camille provided an update for P&A. At the end of the month P&A will wrap up their fiscal year for 2023 and is in the process of finalizing priorities for fiscal year 2024. P&A is seeking public comment on these priorities. Camille will send out a link to the public comment survey. There is potential that P&A may be moving locations at the end of the year.

Developmental Disabilities Council - Jake provided an agency update for the DD Council. The DD Council is collaborating with another statewide advocacy group to improve custody rights for individuals with I/DD. Kentucky's current law allows disability status to be used as justification for termination of parental rights. Twenty-six states have changed these kinds of laws, and a similar change in Kentucky would benefit parents who have I/DD.

The DD Council is working with several different advocacy groups to address the growing waiting lists for waiver services. Steve Shannon from the Kentucky Association for Regional Providers has put together a few plans for aggressively funding the waiting list. The DD Council has focused on educating legislators on the importance of waivers, the cost effectiveness of those services compared to institutions, and ways that administration of waivers can be improved.

The DD Council is also working to educate legislators about loopholes in last session HB238. The bill sought to prevent discrimination against people with I/DD in organ transplantation. However, doctors can still use 'quality of life' judgements to get around this statute.

Division of Developmental and Intellectual Disabilities – Cathy provided an update for DDID. DDID has experienced several leadership changes since the last CAC meeting. Dr. Katie Marks is the new Commissioner of our Department for Behavioral Health, Developmental and Intellectual Disabilities. Click here to learn more about Dr. Marks. Within our division, Claudia Johnson, who was our director, has retired and Elizabeth Kries, who was our assistant director and waiver manager, has accepted a position in HDI. Crystal Adams accepted a promotion to Assistant Director. Crystal is

currently also serving as acting director. Elizabeth Markle has been promoted to the waiver manager position.

Several staff members have been participating in meetings to streamline and improve waiver services. Recommendations will be provided to Medicaid once these meetings conclude.

Office of Vocational Rehabilitation – Jonathan provided an update for OVR. OVR continues to work with individuals who have disabilities to help them get jobs. OVR is currently focusing on working with transition age youth by helping students get into a career path at a younger age. OVR continues to work on implementing a new case management system that should help things move a little quicker.

8) Joint Council meeting discussion
-Input and feedback from CAC members

Elizabeth Kreis

Elizabeth asked the CAC members for insight on important areas for research, support, and funding.

9) New Business and Announcements

Skylar Pash

Walt announced two HDI seminars that will happen on October 20th and November 3rd. Both seminars are being held on Zoom at 1pm EST.

Skylar made a motion to adjourn the meeting, and Vivian seconded. The meeting adjourned at 1:38 pm.

NEXT CAC MEETING: Monday, December 4th, 2023, at 10:30 AM – 1:30 PM