HDI Consumer Advisory Council Hybrid meeting Monday, September 8, 2025 10:30AM – 1:30PM

In attendance today...CAC Members

Jake CruzCathy LerzaJoshua SeigleRobin OsborneBobby BegleyBecky BarnesKristen BeachMegan AckermanRobin HalvorsonBithinny McKeeAndrea StrassburgWalt Bower

Presenters: John Hill, Laura Butler, Haley Potter, Bailey Patterson, Kristen Dahl, Elizabeth Kries

1) Welcome & Introductions

Joshua Seigle

Joshua opened the meeting at 10:30 AM. The members in attendance introduced themselves.

2) Review and Approval of June minutes

Joshua Seigle

Joshua made a motion to approve the minutes. The June meeting minutes were approved.

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

Joshua Seigle

Joshua led the COLA update by reporting that the Association of University Centers on Disabilities (AUCD) will not be holding an annual conference in Washington, D.C. this year due to uncertain funding. Joshua then discussed the leaderships team roles and open positions at the Council on Leadership in Advocacy (COLA). The open leadership team roles are family co-chair, self-advocate co-chair, family co-secretary, and self-advocate co-secretary. Regional representative roles and council trainee representative are also open positions at COLA. Joshua also added that a letter of support would be needed for the open positions at COLA. Chase Mulvaney with AUCD can provide additional information about the leadership team roles and open positions at COLA. Joshua will attend the next COLA meeting, as the CAC representative, scheduled virtually for November 3 from 3:00pm to 4:30pm.

4) Engaging the CAC by-laws update
-Input and feedback from CAC members

All

Joshua made a motion to approve the revised CAC by-laws. Cathy seconded the motion. The members voted on the revised CAC by-laws and the revised CAC by-laws were approved.

5) Stigma Silenced: A Mental Health Podcast
-Input and feedback from CAC members

Haley Potter Bailey Patterson

Haley Potter shared an overview of the Stigma Silenced podcast as well as the application process and interview process. The Stigma Silenced podcast is dedicated to amplifying the stories of Kentuckians with highly stigmatized mental health conditions. It seeks to highlight and center conversations about these highly stigmatized disabilities by bringing people with lived experiences to the forefront. It also seeks to expand the scope of the mental health awareness conversation.

6) Bluegrass Mountain Biking Accessibility Initiative project update -Input and feedback from CAC members John Hill

John Hill provided a Bluegrass Mountain Biking Accessibility Initiative project update. The project is a Fund for Excellence project funded in 2022 and is still going strong with the support of partners. The trail, located at Woodford County Falling Springs in Versailles, Kentucky, is designed with the interest of people with disabilities at the forefront, prioritizing input and feedback from trail users with disabilities. UK Healthcare (Healthy Kentucky Initiative) has provided funds for installing two bike lockers and the purchase of two adaptive mountain bikes at the trail site. An Engage grant proposal was submitted through the UK College of Agriculture to provide funds to host an adaptive mountain bike clinic/workshop at the trail site.

- 7) Break (12:00)
- 8) Working Alternatives to Guardianship
 -Input and feedback from CAC members

Laura Butler

Laura Butler reported that the goal of this project is to form a workgroup of stakeholders that will work together to inform workable decisional support options

for people who have not traditionally had viable options beyond legal guardianship. Laura also shared that they are currently working to get the word out to community groups about the myths around guardianship. All changes to a guardianship must be done through the courts. At any time, the person under guardianship, the guardian or conservator, or any interested party may request a change in guardianship. This project furthers HDI's mission of building inclusive communities by helping identify ways for more people to experience full personal and civil rights.

9) Rooted & Rising project update
-Input and feedback from CAC members

Kristen Dahl Elizabeth Kries

Kristen and Elizabeth provided an update on the Rooted & Rising project. Rooted & Rising focuses on understanding the needs and gaps of mental health services for people with developmental disabilities in Appalachian counties in Kentucky. Its work will be guided by people with lived experience to ensure the voices of rural Kentuckians with developmental disabilities lead the work in making mental health supports and services easier to access.

Rooted & Rising is hosting eight focus groups to gain insight from Appalachian Kentuckians with lived experience. The information shared in the focus groups will be used to create a survey. The survey will be distributed across the region and the results will be used to identify ways Rooted & Rising can best help people with developmental disabilities get the mental health care they want and need.

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

Protection & Advocacy – Robin Halvorson reported the Protection Advisory Council (PAC) starts October 1. Robin also shared the Camille Collins is now the assistant executive director at Kentucky Protection & Advocacy. Robin also reported that PAMI received a significant reduction in federal funding.

Commonwealth Council on Developmental Disabilities - Jake Cruz shared that CCDD had its quarterly meeting May 21. They elected new officers. Amy Smith was elected as Chair and David Allgood was elected as Vice-Chair. Jake was elected as the Vice-Chair of Public Policy. CCDD participated in the Tri-Agency Network meeting on May 22, 2025.

Division of Developmental and Intellectual Disabilities – Cathy Lerza reported that DDID is working with the Kentucky Department for Medicaid Services (DMS) on two new programs: The Community Health for Improved Lives and Development (CHILD) waiver program serves individuals aged 21 and younger. The proposed waiver will provide 1915(c) Home and Community Based Services (HCBS) to children, youth, and young adults with multi-system needs and complexities. DMS collected public comments on the proposed waiver as part of the process for receiving approval from the Centers for Medicare and Medicaid Services (CMS). The public comment period ended July 15, 2025, and the formal response is now available for review.

Proposed CHILD Waiver Public Comment Response
Proposed CHILD Waiver Application
Proposed CHILD Waiver Summary

The 1915(i) RISE (Recovery Independence Support Employment) program serves adults with serious mental illness (SMI) https://dbhdid.ky.gov/1915iriseinitiative. They provide the following services: Assistive technology, case management, housing and tenancy, non-medical transportation services, medication management, and planned respite for caregivers. Participants must qualify for Medicaid to be eligible.

Office of Vocational Rehabilitation – Kristen Beach provided an update for OVR. Kristen shared that OVR is in an order of selection system due to a shortage of funds and financial constraints. New participants will be added to the waitlist. OVR is currently in the process of revising its priority categories, with additional information available on their website.

11) New Business and Announcements

Joshua Seigle

Walt announced the first HDI seminar in the HDI Fall Seminar Series. The title of the first HDI seminar is "Improving Transition Outcomes for Youth with Disabilities" and will be held on September 24, 2025, at 1-3pm ET. Walt also announced that he will send out the registration link and session description for this HDI seminar to the Consumer Advisory Council listsery.

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

NEXT CAC MEETING: Monday, December 1, 2025, at 10:30 AM – 1:30 PM