

HDI Consumer Advisory Council
Hybrid meeting
Monday March 3, 2025, 10:30AM – 1:30PM

In attendance today... CAC Members

Jake Cruz
Brie Alsip
Joshua Seigle
Bobby Begley
Kristen Beach

Bithinny McKee
Camille Collins
Walt Bower
Katie Looney
Robin Osborne

Presenters: Johnny Collett, Rachael Corriveau, Michelle Lowe, Chelsea Naugle, Krystal Wells, Nicholas Wright

1) Welcome & Introductions Joshua Seigle

Joshua opened the meeting at 10:30am. All members introduced themselves.

2) Review and Approval of December Minutes Joshua Seigle

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

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

As the COLA representative for the Consumer Advisory Council, Joshua detailed the proceedings of the COLA meeting. Project LEND is working on an online art archive for individuals with disabilities to contribute to the archive. Individuals will be able to submit art, photos, paintings, and images. The Olmstead needs assessment data was re-presented and will be used for another project in the works. The Public Policy council liaison presented at the COLA meeting. Autism CARES Act was passed and authorized. The Multicultural Council (MCC) is on pause per the liaison. The Leadership Academy Summit application closes on March 3. The Disability Policy Summit will be April 7-9 in Washington, D.C. The Steering committee meeting occurs on March 3.

- 4) Federal events update Johnny Collett
-Input and feedback from CAC members

The University is monitoring executive orders as the orders are being issued and challenged in courts. University representatives are in Washington and Frankfort to advocate for the University of Kentucky. Updates from UK, President Capilouto, and the UK Public Relations team following executive orders are posted at this link: https://pres.uky.edu/monitoring-federal-changes-2025?j=822205&sfmc_sub=251284828&l=21_HTML&u=34270933&mid=10966798&jb=7005. Johnny also mentioned to be mindful of bills coming through at the state level, too; the University of Kentucky is trying to remain on top of legislation at this level as well. There are no discussions with eliminating funding from IDEA. There are federal talks with moving some Department of Education groups to other agencies, but there has not been action yet.

- 5) Child Care Aware Sensory Aware Rachael Corriveau
Project update Michelle Lowe
-Input and feedback from CAC members

Rachel Corriveau and Michelle Lowe presented an overview of the multi-sensory outdoor environment at Children's Learning Tree, a childcare facility for ages birth to 12, in Somerset, Kentucky. Health and safety coaches provide technical assistance to childcare providers across Kentucky; all services are at no charge through HDI. The purpose of the project is to provide a calming and stimulating space for young children and staff who need a quiet break.

The center director requested help with updates and changes to their current natural playground. Updates included taking advantage of the existing space by adding a planter box, remaining mindful of supervision issues with new additions, creating a digging pit for sensory stimulation, adding child-friendly seating, creating a sensory walk section, and adding color to the walls and sidewalk. The project is currently on hold with the weather, but the center director and landscaping team are continuing to discuss how to move forward. CAC members provided feedback and suggestions.

- 6) Break (12:00)
- 7) Agency Updates (P&A, DD Council, DDID, OVR) Each agency

Office of Vocational Rehabilitation – Kristen Beach provided an update for OVR. OVR ended 2024 having served 3,000 more consumers than last year. OVR is continuing work on the new case management system with implementation scheduled for spring. Public forums were recently held about implementing an order of selection as a mechanism to deal with the lack of funds to continue serving people with disabilities. Training with the new case management system is the current major focus.

Commonwealth Council on Developmental Disabilities - Jake Cruz reported that there are upcoming meetings at the Capitol with district representatives and senators to share advocacy goals and priorities, including stressing the importance of retaining Medicaid funding. A Developmental Disabilities network meeting (P&A, HDI, and DD council) on May 21. The DD Council is not participating in the Disability Policy Summit this year as a show of solidarity with the National DD Council. Disability Awareness Month is now recognized as Disability Month per guidelines from the National DD Council.

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| 8) | Practical ASL presentation (12:30)
-Input and feedback from CAC members | Chelsea Naugle
Krystal Wells |
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Chelsea Naugle and Krystal Wells facilitated a discussion of American Sign Language (ASL). They began by debunking ASL myths. For example, ASL is not a universal language, and not all deaf people use ASL. Also, and it is not English on the hands, ASL has its own grammar. There are five parameters for using ASL: Hand shape, palm orientation, hand location, movement, and non-manual signs like facial expressions. A note on language was to use deaf to refer to this community, not hearing impaired. Attendees learned signs for please, thank you, hello, work, and nice to meet you. Tips for alternative communication to sign language were writing, typing, and speech-to-text.

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| 9) | Patient Centered Outcomes Research
Institute (PCORI) project update
-Input and feedback from CAC members | Nicholas Wright |
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Nicholas Wright presented the PCORI project titled, “Convening to Identify Patient-Centered CER Priorities for Black and Hispanic Parents of Children with Disabilities.” Nicholas Wright, Stephanie Meredith, and Sonia Chavez are working together on the project. Project collaborators include National Down Syndrome Congress, Down Syndrome Medical Interest Group, Down Syndrome Achieves, Lumind IDSC Foundation, and the Black Down Syndrome Association. Previous

research shows significant health disparities between Black and Hispanic children with Down Syndrome. Past research relied on advocacy organizations for recruitment. However, representation will be improved by creating race/ethnicity affinity groups. Activities include hosting a 4-hour online community conversation with leaders, hosting a 2-hour breakout session at the National DS Congress Convention, and developing a research brief with a strategic plan for future engagement. The projected outcomes include providing PCORI research fundamentals training, developing a research priority report summary, and publishing a research brief with a strategic plan for future patient centered CER.

10) Engaging the CAC by-laws update Joshua Seigle

Walt reported that there is an updated draft of the CAC by-laws and will send it to the CAC listserv for the CAC members to review prior to the discussion of the CAC by-laws at the next CAC meeting.

11) New Business and Announcements Joshua Seigle

Walt announced two upcoming HDI seminars in the HDI Spring Seminar Series titled, "Supporting the Development of Communication in Children with Disabilities" on March 7, and the "Medicaid Waivers" seminar on April 11. Walt will send out the announcements and registration links for the seminars to the CAC listserv.

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

NEXT CAC MEETING: Monday, June 2, 2025, at 10:30 AM – 1:30 PM