

**HDI Consumer Advisory Council
Online meeting via Zoom
Monday, March 1, 2021 10:30am – 1:30pm**

In attendance today... CAC Members

Vivian Lasley
Skylar Koehler
Morgan Crawford
Cathy Lerza
Jennifer Hicks
Carrie Stith-Webster
Sherece Cole
Lee Gordon
Walt Bower
Joe Cowan
Jonathan White
Meghan Ackerman
Jay Tyner-Wilson
Emily Moseley

Presenters: Tony Lobianco, Jacqui Kearns, Christine Hausman, Arsene Kabeya
Guest: Megan Russell

1) Welcome & Introductions Vivian Lasley

Vivian Lasley began the meeting. All members introduced themselves.

2) Review and Approval of December Minutes Vivian Lasley

Vivian asked for members to review the December minutes. Joe made a motion to approve the minutes, and Jay seconded.

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

At the last Council on Leadership in Advocacy (COLA) meeting, members discussed plain language definitions and the future of making information accessible. They are considering meeting monthly to discuss further definitions of plain language, utilizing funding for plain language, and including a diversity and inclusion plan. The goal is to make plain language accessible to everyone. They are trying to come up with a definition and training around plain language. They are also committed to bringing diversity and inclusion into plain language conversation, so no one is left out. Walt shared with the CAC members that there is a plain language toolkit as a resource on the UCEDD Resource Center website.

- 4) Kentucky Post School Outcome Study (KyPSO) project Tony Lobianco
-Input and feedback from CAC members

Tony Lobianco reported that the state of KyPSO is strong. Data has been collected on outcomes for students with IEPs for 11 years, including data on indicators 14A, 14B, and 14C. 14A is for students with IEPs who went on to higher education. 14B includes students with IEPs who went on to higher education or competitive employment. The 14B numbers have also dropped off in the last years, but this reflects changing the definition of competitive employment to make it more restrictive. 14C is for students with IEPs who went on to higher education, competitive employment, or other employment or education.

Tony presented data from the 2020 YOYO (Youth One Year Out) survey. Tony discussed the value of an alternative diploma. For students with IEPs who received a regular diploma, 23% were in higher education, and 17% had competitive employment. For students who received an alternate diploma, less than 1% were in higher education, and only 5% had competitive employment. Tony was grateful that the first number was not zero, as even less than one percent shows that it is possible. He credits the work of HDI as contributing to that number not being zero.

Tony went on to discuss the value of disclosing a disability in higher education. Only 47% of students with IEPs who enter higher education contact the disability services coordinator at their school. This number of students disclosing a disability has fallen in the last ten years. The data shows that requesting accessibility services during college improves post-school employment, as does academic advising, career services, mentoring, and interning. Working for pay in high school is the best predictor of competitive employment after high school.

Tony opened the floor for questions and comments. Jonathan expressed that the presentation was spot on and that Vocational Rehabilitation is attempting to address these concerns. He also stated that they understand the importance of working for pay in high school. Meghan advocates that students with IEPs also have 504 plans. Lee stated that it is essential to show parents that their child has a path to a job. Joe commented that if parents are informed, they can prepare their child for more independence and suggested bringing the IEP to college. Carrie mentioned that teachers struggle to get parents to attend IEP meetings, and Vivian emphasized establishing relationships with the parents while the child is young.

- 5) Teaching Age Appropriate Learning through Communication (TAALC) project Jacqui Kearns
-Input and feedback from CAC members

Jacqui Kearns shared that the TAALC program focuses on improving communication outcomes for students who need communication support. She said that most of the kids who participate in alternative assessments are verbal communicators. The statistics stay the same throughout elementary and high school, which shows that there is not much improvement. Transition outcomes are not great for kids who do not use expressive communication.

In 2008, the program built a tiered model of intervention which included specialized intervention and advanced training. TAALC is working on ten modules with ASHA credit. The first six modules comprise Tier 1, and they are up and running. Tier 2 is advanced training through six live training webinars, and they are working on these now.

TAALC is also beginning a Project ECHO in AAC in March 2021. The ECHO model is an inter-professional practice based on an 'all teach, all learn' model. It is case-based learning, comprised of six sessions. Jacqui asked for questions and suggestions from the CAC members. Morgan asked if they were in California, and Jacqui said that they were not yet. Morgan noted that Jane Kleinert made her first AAC board. Vivian said she went to the Core Vocabulary training and it was a life-changer.

- 7) Learn the Signs. Act Early. Christine Hausman
-Input and feedback from CAC members Arsene Kabeya

The CDC developed Learn the Signs, Act Early in conjunction with the Association of University Centers on Disabilities (AUCD) and the National Center for Birth Defects and Developmental Disabilities (NCBDD). Learn the Signs, Act Early is designed to help families learn how to monitor their child's development. It is vital to act early as early intervention can significantly impact a child's ability to learn new skills and reduce the need for costly interventions over time.

The Milestone Checklists are for use for children between the ages of two months through five years. The Milestone Moments Booklet has the same vocabulary as the checklists. It also gives activities that you can do with your child. There is also a Milestone Tracker app, which is the most popular. It can track multiple children and offers tips and activities. It helps parents know when to 'act early' and tracks doctor's appointments. They also have children's picture books for ages 1-3 with developmental milestones built into the story.

Christine asked for suggestions from CAC members to extend their reach. Megan Russell suggested Kentucky Refugee Ministries. Vivian suggested Head Start programs. Meghan shared that she feels these checklists can be triggering when a parent answers with a no consistently and asked if there are resources to help with parent's anxiety when their children are not meeting the milestones. Christine replied that the CDC is aware of this, and they are working on being more sensitive to this issue. Meghan also suggested that they reach out to parenting and pregnant teens programs in the state. Vivian suggested utilizing social media and the health department. Meghan suggested mental health providers, OBGYNs, and neonatal intensive care units (NICUs). Walt suggested reaching out to the Childhood Development Center of the Bluegrass.

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

Division of Developmental and Intellectual Disabilities – Cathy Lerza reported a resolution has been submitted to the legislature for a Waiver Redesign Task Force:

<https://apps.legislature.ky.gov/record/21rs/hcr55.html>. The Waiver Redesign Task Force is to be more inclusive in waiver redesign efforts by involving families and people with disabilities in this effort. Cathy also reported studies show people with developmental and intellectual disabilities are more likely to be exposed to COVID-19 and have poorer COVID-19-related health outcomes than the general public. The DDID has been working diligently to mitigate those issues by urging providers and families to follow state and CDC guidance. They have worked hard to have staff who work with people in the waivers be eligible to receive the vaccine in the same grouping as health care workers. They have also worked to get people receiving services included in getting vaccines – most who receive residential services have been offered the vaccine and are now working on getting vaccines for those not in residential services.

Office for Children with Special Health Care Needs - Lee Gordon reported they are still providing outpatient services in clinics across the state. Some of the outpatient services are in person, and others are telehealth. Sondra Gilbert is connecting people to services they need. They are helping parents to deal with schooling at home issues.

- 9) Election of New CAC member All

The CAC Nomination committee met and nominated Karen Lane for election to the Consumer Advisory Council. Walt shared a biographical sketch of the nominee with the CAC members. Vivian made a motion to elect Karen Lane to the CAC, and the motion passed unanimously.

- 10) Election of New CAC Vice-Chair and Chair All

Joe Cowan was elected to serve as Vice-Chair of the CAC and Morgan Crawford was elected to serve as Chair of the CAC.

- 11) New Business and Announcements Vivian Lasley

Walt shared information about the upcoming HDI Seminar Series with the CAC. On Friday, March 12 is “The Helen Keller Dilemma: Workplace Discrimination in Vision and Hearing Loss in America” seminar and on Friday, April 16 is the “Job Accommodation Network (JAN): Your Resource in Challenging Environments” seminar.

Emily noted that this would be her last meeting as the student representative on the CAC. She thanked members for their hard work on the CAC and stated that she had learned a lot from her time here as the student representative. She will miss being a part of the CAC and hopes to work with the CAC in the future.

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

NEXT CAC MEETING: Monday, June 7, 2021 at 10:30 AM – 1:30 PM