

**HDI Consumer Advisory Council
Online meeting in Zoom
Monday June 7, 2021 10:30AM – 1:30PM**

In attendance today... CAC Members

Morgan Crawford
Vivian Lasley
Jay Tyner-Wilson
Joe Cowan
Skylar Koehler
Walt Bower
Lee Gordon
Kathy Sheppard-Jones
Karen Lane
Jennifer Hicks
Phil Rumrill
Cathy Lerza
Madison Yee

Presenters: Jason Jones, Teresa Belluscio, Carolyn Wheeler

Guests: Megan Russell, Abby McHenry

1) Welcome & Introductions Morgan Crawford

Morgan Crawford began the meeting. All members introduced themselves.

2) Review and Approval of March minutes Morgan Crawford

Morgan asked for members to review the March minutes. Cathy made a motion to approve the minutes, and Vivian seconded.

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

Walt provided an overview of the Council on Leadership in Advocacy (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 Council on Leadership in Advocacy also builds the capacity of people with disabilities and family members to participate in program planning, research, evaluation, and public policy. 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, AUCD Councils and Committees, AUCD Special Interest Groups, and other advocacy opportunities.

- 4) Southeast ADA Center
-Input and feedback from CAC members

Jason Jones

Jason Jones introduced the Southeast ADA Center as a part of the Burton Blatt Institute at Syracuse University. Burton Blatt, the former Dean of Syracuse University School of Education, brought public attention to thousands of individuals living in institutional purgatory. Jason played a short video of President George H.W. Bush giving a speech following the signing of the Americans with Disabilities Act (ADA).

The purpose of the Southeast ADA Center is to facilitate voluntary compliance with the The Americans with Disabilities Act of 1990. They also conduct research to reduce and eliminate barriers to employment and economic self-sufficiency for Americans with disabilities. Jason noted that most employers and companies are unaware of noncompliance with ADA and are quick to comply with changes to increase accessibility.

The main office of the Southeast ADA Center of Kentucky is in Lexington, Kentucky. The Southeast ADA Center answers questions about ADA, disseminates materials/information, provides education and training, and increases public awareness. Jason then further discussed the core functions of the Southeast ADA Center: provide technical assistance on the ADA, conduct training on ADA using synchronous and asynchronous platforms, and provide knowledge translation via a broad network of dissemination partners and multi-media outlets.

www.adachecklist.org is a website where state and local governments, businesses, and non-profit organizations can see how compliant they are with regard to ADA. The ADA checklist is a Word fillable form that businesses can use to ensure that they are following accessibility guidelines as stated in ADA. Jason noted that the ADA checklist is a helpful resource, but should not be used as a full compliance document.

Jason opened the floor for questions and comments. Walt noted a helpful and informative ADA talk he attended by the Southeast ADA Center on service animals. Jason announced the next ADA talk is on Thursday, June 24th on ADA and Employment. Morgan asked about BCTC's program for individuals with disabilities and Kathy provided Morgan with contact information. Joe asked about whether or not businesses comply when you write them a letter about noncompliance with ADA. Jason replied that when you are non-confrontational, such as writing a letter, most businesses are understanding and willing to make changes. Jason closed his presentation by communicating his appreciation to the CAC members.

- 5) Project RETAIN update
-Input and feedback from CAC members

Kathy Sheppard-Jones

Kathy presented updates on Project RETAIN. She also thanked the CAC members for their time and commitment. Kathy began by emphasizing the high frequency of occurrence of American workers leaving the workforce due to injury or illness. Kathy stated the purpose of Project RETAIN through early intervention and the participant criteria. The RETAIN Kentucky Phase 2 grant was approved for \$21.6 million per year for approximately four years. The purpose of Phase 2 is to scale delivery of return-to-work/stay-at-work services to people who have an

injury/illness that makes it difficult to work. Kathy announced an upcoming seminar by Matthew D. Adamkin, M.D. on June 21. Kathy asked for input on how to spread the word of Project RETAIN Kentucky and noted to email her with any ideas.

Kathy also introduced the Kentucky LEND grant. The LEND grant is a training program for 9 graduate student trainees annually. The training program takes an interdisciplinary approach with a multitude of national partnerships and state and university partnerships.

- 6) 2021 Summer Leadership Experience Teresa Belluscio
-Input and feedback from CAC members

Teresa introduced the 2021 Summer Leadership Experience camp. The camp is for Kentucky high school students (entering juniors through seniors) with disabilities. The Summer Leadership Experience camp prepares students to make the transition to the next level of education, which may lead to a career. The student must be between the ages of 14-21, enrolled in an educational setting, have a documented disability, and is working with VR.

Teresa discussed the variety of resources and speakers who will attend the camp. Morgan asked about being a mentor and Teresa provided a description of the responsibilities of a mentor. Another question was asked about other opportunities for older students/young adults that resembled the Summer Leadership Experience. Teresa ended her presentation by asking CAC members to share the flyer for the camp to those who might benefit from the camp.

- 7) Employment Education Program Carolyn Wheeler
-Input and feedback from CAC members

Carolyn introduced the Employment Education Program funded by the Commonwealth Council on Developmental Disabilities. The current presentation is on employment benefits and how work and social security benefits can work together. Carolyn utilized a poll to gather how much the CAC members understood about social security benefits. The majority of the group knew two programs existed, but did not exactly know how they functioned. Carolyn shared a personal story that led to her knowledge of social security benefits (SSI/SSDI), home ownership, and retirement plans for individuals with disabilities.

Carolyn shared results from a survey she sent out the previous year related to work and social security benefits. Results from the survey indicated many individuals were very interested in learning more about social security benefits and would be willing to spend 10 minutes or more to do so, yet have not spent that time. The vast majority of respondents reported that they would feel more confident if they knew more information in relation to social security benefits.

A second poll was administered to the CAC about their favorite sport to watch/play. Carolyn explained how each sport, although all played with a ball, is complicated in its own way. She made an analogy about learning complex rules. A final poll was administered about eagerness/willingness to learn and get paid to disperse information about social security benefits. Carolyn informed the group of the opportunity to become an employment education ambassador. A training must be completed to become an employment education ambassador. Once

completed, individuals may get compensated for being an ambassador. Lee posed a few questions about becoming an ambassador.

Finally, Carolyn shared the ky.db101.org website that explains the “101” of disability benefits. Walt brought up STABLE accounts. Carolyn briefly described the STABLE Act, shared the website, and the STABLE Kentucky fact sheet. Lee posed one last question about SSI/SSDI and Carolyn answered the question. Carolyn expressed her appreciation to the CAC members and concluded her presentation.

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

Division of Developmental and Intellectual Disabilities – Cathy Lerza shared that they are in the process of returning to in-person waiver services. Providers are being encouraged to incorporate any changes implemented during the pandemic that have proven to be beneficial (i.e., technology and outdoor activities). DDID, DCBS, and the CMHCs are working together to improve services for youth with intellectual and developmental disabilities who are in DCBS custody and to improve the process for transitioning to the SCL waiver when they age out of being in DCBS custody. DDID is working with HDI and other partners on project CHEER. Project CHEER (which stands for Community Health Education and Exercise Resources), is Kentucky’s State Disability and Health program funded by the Centers for Disease Control. They did some health challenges during COVID and will be continuing with weekly challenges. The current challenge, regarding hydration, is to set a goal for how much water to drink each day and keep a log to chart your progress.

Office for Children with Special Health Care Needs - Lee Gordon reported that they are continuing to promote their services and are now providing in-person services. OCSHN is also having telehealth trainings to help individuals understand medical telehealth services better and receive access to healthcare. Lee will send information on trainings to Walt to send to the CAC members.

- 9) New Business and Announcements Morgan Crawford

Walt mentioned the upcoming Employment Seminar Series with Matthew D. Adamkin, M.D. on June 21st from 4:00-4:30pm. Walt provided the registration link to the Employment Seminar Series to the CAC members in the chat box. In a second announcement, Walt noted the upcoming ADA talk on June 24th.

Morgan made a motion to adjourn the meeting, and Jay seconded. The meeting adjourned at 1:15pm.

NEXT CAC MEETING: Monday, September 13, 2021 at 10:30 AM – 1:30 PM