

**HDI Consumer Advisory Council
Coldstream Training Room
Monday December 2, 2019 9AM – 1 PM**

In attendance today... CAC Members

Morgan Crawford
Joe Cowan
Cathy Lerza (for Claudia Johnson)
Vickey Reilly
Carrie Stith-Webster
Vivian Lasley
Walt Bower
Camille Collins
Emily Moseley
Skylar Koehler
Lee Gordon
Jay Tyner-Wilson

Guests: Chrissy Shewell, Sonia Withers, Megan Russell, Julie Pash

Presenters: Caroline Gooden, Jennifer Ulbricht, Christina Espinosa Bard

Technical and other assistance: Maurice Dawson and Judy Johns

1) Welcome & Introductions Joe Cowan

Joe Cowan began the meeting. All members introduced themselves.

2) Review and Approval of September Minutes Joe Cowan

The CAC members reviewed the September minutes. The review of the September minutes included the following 2 corrections: (1) The SIS Assessment will be moving from a two-year cycle to a three-year cycle. The American Association on Intellectual and Developmental Disabilities (AAIDD) completed studies that show the people's needs are stable for over three years. (2) Lee replied that we do provide hearing services to newborns, but he stated that we do more than provide hearing tests. Vivian Lasley moved to accept the minutes and Carrie Stith-Webster seconded. The motion passed and the minutes were accepted with the corrections noted.

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

Sherece Cole will be added to the COLA listserv so will be able to provide a COLA update at our March CAC meeting. Dorothy Garcia at AUCD is confirming that Sherece has been added to the COLA listserv.

4) AUCD Update – 2019 AUCD conference update

Joe Cowan

Joe Cowan attended the 2019 AUCD conference in Washington, D.C. and provided an update on the Council on Leadership in Advocacy, also known as COLA, meeting and the AUCD conference. Joe participated in breakout groups at the COLA meeting. Groups discussed the role and responsibilities of the three regional COLA representatives. Currently, there are three regions in the United States, with one COLA representative from each region. The consensus from the breakout groups was that the three regions were too large to adequately represent each region. Joe also reported there was an emphasis at the AUCD conference to build the capacity of network members advisory committees.

5) Self Advocacy Toolkit update

Jennifer Ulbricht
Caroline Gooden

Jennifer Ulbricht provided a comprehensive overview of the self-advocacy toolkit. Identifying a need for accessible resources, Jennifer explained that the self-advocacy toolkit provides hard copy and electronic resources to develop advocacy skills for people with disabilities.

After receiving feedback, the self-advocacy toolkit is now accessible to all people. The self-advocacy toolkit is designed for Kentucky, but it is applicable to other states as well. The contents of the toolkit include: Define terms, Key facts about the history of advocacy, Identify strengths and needs for advocacy, Identify advocacy goals, and Identify resources to achieve goals.

There is an opportunity for persons to develop their own SMART (Smart, Measurable, Attainable, Relevant, Time-Based) goals. There is also space to identify people who can help one achieve their goals. Inspirational quotes are included to help people learn to be bold and speak up for themselves. Jennifer emphasized that the toolkit, by design, is not meant to be completed in one day. In the early stages of developing the toolkit, HDI's Consumer Advisory Council members provided feedback and comments. Morgan provided feedback about font size and wording.

Jennifer stated there was an opportunity to apply for a poster session at the 2019 AUCD conference to present the toolkit. They applied and the poster was accepted to the AUCD conference. Caroline presented the poster at the AUCD conference and provided a short presentation about the self-advocacy toolkit. A suggestion from a participant at the poster session was to include a video connected to each section of the toolkit. The self-advocacy toolkit also includes a list of resources.

There was lively discussion following the presentation of the self-advocacy toolkit. CAC members suggested that the self-advocacy toolkit be shared with high school students as well as adults who could benefit from the information. One CAC member suggested they share the self-advocacy toolkit at the Arc of Kentucky's annual conference in Louisville. CAC members suggested the following organizations to share the self-advocacy toolkit with: Bluegrass Area Development District, New Vista, and Centers for Independent Living in Kentucky.

- 6) Election of new CAC Vice-Chair, Chair and Setting of 2020 Meeting Dates All

Vivian Lasley was elected to serve as Chair of the CAC for 2020. Morgan Crawford and Jay Tyner-Wilson were nominated to serve as Vice-Chair of the CAC for 2020. An election will be held to determine the CAC Vice-Chair for 2020.

The dates for the CAC meetings in 2020 are March 2, June 1, September 14, and December 7.

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

Protection & Advocacy – Camille Collins reported that P&A represented over 300 individuals with disabilities on issues including, but not limited to: education rights, Olmstead, Medicaid denials, seclusion in prisons, and abuse and neglect. P&A provided 485 Information & Referrals (calls) on the issues mentioned above. Camille also shared that P&A provided 18 trainings to 511 individuals throughout Kentucky on Supported Decision-making, guardianship, education right, KY Stable, and others. She also reported that P&A monitored various settings that serve people with developmental disabilities to ensure that people understood their rights and to ensure people are free from abuse and neglect. Facilities monitored during this quarter included, but not limited to, include: Oakwood ICF, Bingham ICF, various residential programs under the Brain Injury Waiver, Private Child Care facilities, Personal Care Homes, and Adult Day Training programs. Camille also reported that P&A met with Representative Gentry on the future work with the Empower & Engage Caucus and advocated for them to work directly with people with disabilities on all issues. In addition, the PADD Advisory Board met with Representative Mark Hart from Pendleton County and provided feedback and information about a possible future Bill of Rights. Camille announced that P&A is working with other members of the National Disability Rights Network and Rooted in Rights (Disability Rights Washington), to create a video on alternatives to guardianship, including Supported Decision Making.

Division of Developmental and Intellectual Disabilities – Cathy Lerza reported that DDID continues to be involved in waiver redesign. The Kentucky Department for Medicaid Services (DMS) contracted with Navigant Consulting. Navigant is holding meetings with staff from DMS, DDID, and the Department for Aging and Independent Living. Waiver changes have been submitted for public comment. Proposed regulation changes will also have a public comment period. The changes are expected to take place by mid-2020.

- 8) New Business and Announcements Joe Cowan

Walt Bower provided information regarding the upcoming HDI Fall Seminar, ‘How to Navigate the Muddy Road to Diagnosing Specific Learning Disabilities’ on December 6, 2019 at 1 PM at the UK Coldstream Research Campus in the Human Development Institute Training Room.

Walt also shared that HDI celebrated HDI's 50th Anniversary with a 5K Run, Walk, Stroll on October 12, 2019 and an HDI 50th Anniversary Gala on November 2, 2019. The 5K Run, Walk, Stroll took place at the Coldstream Park, a park in Lexington located on the UK's Coldstream Research campus. There were 122 participants registered for the 5K event. The HDI 50th Anniversary Gala was held at the University of Kentucky's Gatton Student Center. Tickets for the Gala sold out and 200 tickets were sold. The Gala included a silent auction, guest speakers, a live band, and plated dinner.

9) HDI CATS Update

Christina Bard

Christina Bard reported that the HDI Center for Assistive Technology Services (CATS) is the regional Assistive Technology Regional Center (ATRC) serving Lexington and the surrounding region. HDI CATS is one of 56 statewide Assistive Technology (AT) programs.

HDI CATS has a lending library and anyone can create a free account. There are over 1500 items in the lending library at HDI CATS. All loans from the lending library are free and can be checked out for 30 days. The inventory of every AT center in Kentucky is searchable. In addition, HDI CATS has 15 ramps for short term rental.

There are also free assistive technology and durable medical devices distributed through Project CARAT (Coordinating and Assisting the Reuse of Assistive Technology). Items for Project CARAT are provided through donations from the community. If anyone has or knows of anyone who would have items to donate, those donations are much appreciated.

Assistive Technology (AT) is defined as any technological tool used to access education, employment, recreation, or communication to live independently. One of the benefits of AT is that it enhances independence. In 2019, HDI CATS has loaned 342 items and Project CARAT has reutilized 597 items valued at \$338,351.

Christina shared that every fourth Thursday of the month, there are ADA (Americans with Disabilities Act) trainings held at HDI CATS. The trainings begin at 10 AM and all trainings are posted on Facebook. Christina also shared that HDI CATS works with students in courses at the University of Kentucky and with different programs in the community. Recently, HDI CATS worked with an Eagle Scout on a direct service project.

10) Lunch and Further Discussion about CAC
Members' Involvement in HDI Projects

All

Vivian Lasley made a motion to adjourn the meeting and Skylar Koehler seconded. The meeting adjourned at 1:13 pm.

NEXT CAC MEETING: Monday, March 2, 2020, Coldstream 10:30 AM – 1:30 PM, with a working lunch.