

**HDI Consumer Advisory Council
Coldstream Training Room
Monday December 4, 2017 9AM – 1 PM**

In attendance today... CAC Members

Camille Collins
Claudia Johnson
Elaine Brown
Jessica Whitehead
Jennifer Ulbricht
Kathy Sheppard-Jones
Maria Delgado
Jennifer Hicks
Morgan Crawford
Traci Brewer
Walt Bower
Vickey Reilly
Lee Gordon
Stephen Craker

Guests: Kevin Sharkey, Chatia Frazier

Presenter: Chithra Adams

Technical and other assistance: provided by Judy Johns and Maurice Dawson

1) Welcome & Introductions Walt Bower
All members introduced themselves.

2) Review and Approval of September Minutes Walt Bower
The minutes were reviewed. Traci Brewer made a motion to approve and Jennifer Hicks seconded. Correction to the September minutes: The spelling of Kellie McCain's name was corrected.

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

Protection & Advocacy- Camille Collins reported she will send out copies of the P&A priorities through Walt, and those are also available on the P&A website. The DD Network and P&A put on showings of the "Bottom Dollars" documentary. About 150 people came to view the film. Camille stated that she has been working with Jill Hunter and Lori Gresham. They have encouraged P&A's involvement in Medicaid legislature. P&A is also assessing four sites for ADA compliance. In addition, they are developing a resolution apologizing for the neglect and abuse that Kentuckians with disabilities have experienced in the last 100 years. Furthermore, P&A is working on a statutes that needs modification. The statutes currently state that individuals living with developmental

disabilities, intellectual disabilities, or certain mental health disorders do not have the ability to consent to sexual activities or intercourse.

Council on Developmental Disabilities – Jennifer Hicks announced there are six new board members on the DD Council. The most recent council meeting was last month. The new board members are very involved and it reflected in the DD Council meeting. Of the six new board members on the DD Council, three are self-advocates and are also applying to the CAC. An announcement was given that 874K Day is February 31st next year. The DD Council is also producing a video about tips to help develop self-advocacy skills with legislators. There are several other projects that the DD Council is working on. The first is with the ARC of Kentucky to show the “Bottom Dollars” documentary. Another is the Post Cards to Legislators project. Finally, the DD Council is working on closing out the federal reports for the last year.

Division of Developmental and Intellectual Disabilities – Claudia Johnson reported that the department is busy with the opioid response grant that they were awarded. DDID is continuing to work with Medicaid on the waiver redesign. The SCL Waiver is down to only 20 slots so there will be an Emergency waiting list once those slots are allocated. There is a need to support and encourage more funding for waiver slots.

Commission for Children with Special Health Care Needs - Lee Gordon reported that the executive director retired at the end of October and the commission is still waiting to hear about who their new executive director will be. Lee provided a brief overview of the Family-to-Family Grant that is in its 9th or 10th year. There are 50 of these federal grants given across the nation. It is a means to connect new parents to navigate the health care and service provider system with seasoned parents who have navigated the needed services.

Office of Vocational Rehabilitation- Vickey Reilly reported that Ron O’Hair has now replaced Teresa Brandenburg as the branch manager. The executive director position will be posted soon for applications. They are working through the updates for WIOA and seeing how those new regulations updates will take hold.

4) AUCD Update – Council on Community Advocacy Jennifer Ulbricht

Jennifer Ulbricht reported that she attended the AUCD annual conference in Washington DC as the representative from HDI’s CAC. She reported that COCA has formally changed their name to COLA (Council for Leadership and Advocacy). Jennifer also reported that Andy Imparato, the AUCD executive director, discussed the need for more leadership roles and not only parent-advocacy roles. Jennifer discussed how she has personally experienced parent advocates in leadership roles and how they can have some major impacts. This emphasized the move COLA is taking to get parent advocates into leadership roles. They are hoping to create more consumer advisory councils to influence the direction of UCEDD organizations.

Through the AUCD conference, a paper was disseminated entitled “Nothing About Us Without Us: Including People with Intellectual and Developmental Disabilities in Research.” This paper

is meant to be a guide and shows data to support leadership. Jennifer discussed a conference session she went to on Genetic Counseling. There were very few parents in the meeting with most of the attendees having a medical and professional background. However, they were very welcoming of parents and indicated that they want parents at the table because they have something valuable to contribute.

5) Leadership Activity Jennifer Ulbricht

Jennifer led the CAC in a leadership activity. The activity led to a discussion about how other agencies had hosted the “Bottom Dollars” documentary and discussion panels. The documentary can be found by googling rootsandrights.org. This site has suggested discussion questions for panelists after a showing of the documentary. There was also a discussion of the target audience and who would be appropriate/effective panel members.

Kathy Sheppard-Jones suggested showing the documentary and connecting it with the Kentucky Works project to make it more actionable. Jennifer Hicks discussed the DB101.org site that provides personalized information about working, income, and impacts to benefits that may help settle parent’s fear of losing benefits for their child. Elaine Brown developed the discussion further by including the concern of parents only getting employment information in the 11th grade IEP meeting.

6) CAC Group Photo

Group moved outside to take a group photo in a landscape format.

7) Election of New CAC Vice-Chair, Chair and Setting of 2018 Meeting Dates Walt Bower

Walt discussed that the term for the Chair and Vice-Chair had ended and it was time to elect and nominate new chairs. Frank Huffman was nominated for Vice-Chair and Walt will check in with him to see if Frank accepts the nomination. Jennifer Hicks was elected as the Chair for 2018. The 2018 meeting dates are March 5th, June 4th, September 10th, and December 3rd.

8) UCEDD Core grant application – Review and Input from the CAC Chithra Adams

Kathy said that she was excited for this presentation because the CAC will be given the results of the Joint Needs Assessment. Kathy also discussed about how we are now in the 4th year of 5 for funding.

Chithra presented the results from the Joint Needs Assessment from 2017. The survey was given throughout the summer and ended October 1st. This short survey was given in online or paper forms with 467 total participants. Respondents rated their level of need across 10 life domains. Responses for the survey came from all over the state. Fayette, Jefferson and Warren County had the highest participation. The majority of the respondents identified as service providers.

The top five needs for individuals with disabilities are self-advocacy, employment, community supports, transportation, and education. The top needs indicated by families and caregivers were self-advocacy, education/early intervention, employment, and housing. The top needs indicated by service providers were transportation, self-advocacy, education/early intervention, and childcare.

9) UCEDD Core grant application – Review and Input
from the CAC

Kathy Sheppard-Jones

Kathy asked for more input from the CAC as the focus transferred to a grant proposal. Kathy shared the mission, vision, and core goals of HDI. She reviewed that the core goals need to be addressed but the means those are accomplished vary. Kathy discussed some of the pre-service training goals and the ways HDI meets those goals, as well as community services and technical assistance. She covered interdisciplinary research that relates to training, individuals, and the community. She also reviewed the information sharing components of HDI.

Kathy asked the CAC to brainstorm answers to two questions: (1) What do students need to know? (2) How can the CAC be involved? The CAC members worked individually and as small groups before coming back together in a large discussion.

The CAC members suggested that students need to know:

- The whole picture outside of their individual life experience and specialization or an ecological systems view of disability and its components.
- The current state and federal policy that shape the landscape.
- Rights and laws that pertain to education, employment, housing, and rights.
- More than just a 101 course overview, including more application and how the theories and policy actual manifest in the real world.
- Having students, resident trainees, and practicing physicians link to support groups and networks.

The CAC members suggested possible ways the CAC could be involved:

- Pairing students with families for the duration of their training.
- Setting higher expectations for the individuals that they work with.
- Setting more diverse examples. Even when those visions of higher expectations are made and adopted, there is a need to break past the barriers in the way of realizing those expectations. There is a need to start earlier.
- Get CAC members involved in trainings and possibly in the Developmental Disabilities Graduate Certificate program.
- Getting parents to skype/zoom in to relevant topics in the classroom.
- The CAC members will be committed to dissemination of information within respective spheres (platoons) of influence. CAC members would stay accountable by reporting back during the next council meetings. The online guide would be a great thing to share for all members of the CAC. Members would adapt the means of the dissemination for their specific area, such as email or pamphlets.
- CAC members would review the resource manual and online guide to ensure that

the information is current.

Kathy then asked the CAC members to brainstorm answers to two more questions: (1) What do communities need to know? (2) How can the CAC be involved?

The CAC members suggested that communities need to know:

- There is a need for individuals within businesses to learn that it's possible to include persons with disability in the workforce so that business are more open to employment for persons with disabilities.
- Issues surrounding transportation and the transportation system.
- We need to encourage parents to start young and get children out in extracurricular activities and in the communities. Then, the community at large is exposed to the success that individuals can have and they can become a part of that support network.
- It was suggested that community members at large are afraid of saying something politically incorrect and that this fear prevents them from wanting to be involved.

The CAC members suggested possible ways the CAC could be involved:

- Members being a part of the "Bottom Dollars" documentary panels.
- Involvement in the Bluegrass Community Foundation community conversations and replicating its involvement.

The CAC members discussed resources that need to be developed:

- Members suggested disseminating HDI webinars by other means besides the internet for more rural areas.
- Showing recorded seminars in doctor offices.
- Needs to be a focus on self-advocacy and communication skills as seen from the needs assessment.
- Showing short clips and social stories to help show kids how to advocate.
- Helping parents move on from high school perspectives and safety nets and preparing for the next step to a work, employment, and life-skills perspective.
- Advocacy Toolkit Finder as seen at the AUCD conference to learn different ways to self-advocate.

The CAC members suggested possible ways the CAC could be involved:

- The CAC members will be committed to dissemination of information within respective spheres or platoons of influence. CAC members would stay accountable by reporting back during the next CAC meeting. The online guide would be great to share for all members of the CAC. Members would adapt the means of the dissemination for their specific area, such as through email and pamphlets.
- Improve P&A's self-advocacy booklet along with Elaine Brown's binder of resources.
- Submitting a proposal for developing initial resources through the Fund for Excellence.

Kathy stated that if more ideas come up to contact her. And Kathy will be in touch about the Fund for Excellence information.

10) New Business and Announcements Walt Bower
Morgan Crawford presented a free mobile app to the CAC. Access Now is an application for people with disabilities to find out if a business is accessible, such as alternative entrances and accessible restrooms.

11) Special Recognition Walt Bower
Certificates of recognition were presented to Jennifer Mynear and Morgan Crawford for serving as Chair and Vice-Chair.

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

**NEXT CAC MEETING: Monday, March 5, Coldstream 9:00 AM – 12:00 PM,
followed by a working lunch.**

Elaine Brown motioned to adjourn and Traci Brewer seconded the motion.