

**HDI Consumer Advisory Council
UK Coldstream Training Room
Monday September 11, 2017 9 AM – 1 PM**

In attendance today....CAC Members

Camille Collins
Cathy Edwards
Claudia Johnson
Elaine Brown
Jessica Whitehead
Jennifer Hicks
Jennifer Ulbricht
Kathy Sheppard-Jones
Maria Delgado
Morgan Crawford
Traci Brewer
Walt Bower
Leela Raj

Guest: Chatia Frazier

Presenters: Stephanie Meredith, Lindsey Mullis, Megan Jaspersen, Morgan Turner, Amy Cooper-Puckett

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

1) Welcome & Introductions Walt Bower

Walt welcomed the CAC members to the meeting and led the introductions by introducing himself. Members introduced themselves.

2) Review & Approval of June Minutes Walt Bower

Everyone present reviewed the minutes. Jen Hicks made the motion to approve the minutes and Elaine Brown seconded the motion. The motion passed.

3) AUCD Update – Council on Community Advocacy Jennifer Ulbricht

Jennifer Ulbricht announced COCA has had two meetings since the last CAC meeting in June. Overall, activities are in full swing in preparation for the forthcoming AUCD conference on November 5th-8th in Washington D.C. Several sub committees are working on the various details. COCA hopes to have webinars on various topics such as advocacy, leadership, and others and are open to suggestions. Kathy suggested that Jennifer attend the AUCD conference this year too and Jennifer agreed to do so.

4) Kentucky Works website activity Stephanie Meredith

Stephanie Meredith guided members through the various features of the Kentucky Works website. The screen size adjusts itself to the size of the device being used, such as a cell phone or a laptop. The language is at a 3rd grade level and pictures enable accessibility to individuals with intellectual disabilities. One also has the option to go directly to the link displayed below the picture for details on the resource topic.

Stephanie invited questions and feedback from the members. Jennifer Ulbricht mentioned about the parent network trained Kentucky Family to Family Health Information Centers and suggested that they be added to the 'Find Mentors' page of the Family page. Sondra Gilbert and Debbie Gilbert are the co-directors of the centers.

Cathy pointed out that since information linked to 'Resources for Youth' also had information pertinent to self-advocates who are not necessarily youth, the word "youth" needs to be changed. Claudia suggested a separate link to resources for Adults with Disabilities. It was concluded that the word "youth" will be replaced with "People with Disabilities."

Claudia drew attention to the heading 'Kentucky Community Living Medicaid Waiver' on the waiver page commenting that it was popularly referred to as 'Kentucky Supports for Community Living Medicaid Waiver' or SCL Waiver. This also brought home the awareness of differences in vernacular among different states.

Overall, members unanimously appreciated the user friendly and thoughtful features of the website. Stephanie urged members to continue giving her their feedback, resources and stories. Camille suggested the need for everyone to promote the website and the Facebook page and Stephanie requested members to cite the link on their respective website page as well as FB page as well as join their FB page. Kathy added that the website (kentuckyworks.org) is currently featured on AUCD's website.

5) Evaluating the Impact of our Work at HDI Kathy Sheppard-Jones
– Seeking CAC Input

At the outset, Kathy Sheppard-Jones requested members to observe a moment of silence in memory of September 2001. She thanked Chithra for her contribution to furnishing the evaluation data and reviewed HDI's mission: "To promote the inclusion, independence, and contributions of people with disabilities and their families throughout the lifespan. We do this through education, research and evaluation, information sharing, leadership, and advocacy across Kentucky and the nation".

HDI has five major goals and they are around Preservice Training, Community Services Training, Community Services Community Collaboration, Interdisciplinary Research, and Information Dissemination. Each of the five goal areas has 6-8 objectives with an annual target for each objective. Progress is measured in terms of whether targets are exceeded or met, or whether targets are on track or in progress. HDI has met or exceeded all targets for all objectives

except for Medical students training objective within Preservice Training, and the objectives of early childhood special education practices to college faculty and KY's Supported Living Program, KY Supports for Community Living Waiver, and Michelle P. Waiver within Information Dissemination, where targets have not been met.

HDI is now writing out the proposal for the next 5-year Core grant. Needs Assessment surveys have been emailed to everyone to get inputs from people across the state. Kathy also left the members with homework - to think about ways that they could share the survey. She added that the surveys were also available in Spanish and the deadline for submitting the surveys is September 30th. At the next meeting Kathy would like to present the status of their work in writing the proposal and would like to include the CAC's suggestions and advice in the same.

6) Group CAC Photo

7) Break

8) Project Spotlight – Health and Wellness Projects
and feedback from our CAC

Lindsey Mullis
Megan Jaspersen

Lindsey introduced herself and Megan as the persons charged with improving the health and wellness of people with disabilities and their friends, families and caregivers across the state. One of their projects is called Health Partners. Megan then took the floor with Morgan Turner, to present the Health Partners project.

Megan and Morgan introduced themselves to the members. The project is based on a curriculum called Healthy You Lifestyles designed by the Oregon Health & Science University (OHSU) which was originally created just for individuals with disabilities. However, after studying it, they adapted it to cater to anybody - individuals with or without disabilities - in order to have a greater impact and reach. Morgan is one of the self-advocates. In addition, Monica, Megan and Brandy have been hired for the project and travel along with her across the state to co-facilitate the program.

The curriculum spans twelve hours and is holistic and besides physical health, it also focuses on social health, emotional health, and spiritual health, and the importance of being involved in meaningful activities. Goal setting is the last component of the program. The program is individualized and self-determined. After the information is provided, each individual participant decides what they would like to work on and set their own goals.

The programs are conducted in community locations to be more inclusive and have a wider reach. The core aspect of this program is the 6-month follow up meetings. After the goals are set, the team continues to meet with the participants once a month, which ensures accountability. The follow up meetings entail checking in on the participants, understanding what they require to accomplish their goals, and additional community activities such as yoga, cooking, and park days.

Programs have been offered in several communities across Kentucky. Participants can also choose any activity from the curriculum that they would like to pursue following which connections are enabled with the service providers within the community, which further helps with sustainability. Data analysis of the programs across the various communities to evaluate the success of the widespread programming is the next immediate step.

The team is currently working on rolling out the Train the Trainer module across the state of Kentucky for which Megan has undergone training. Megan is hopeful that other people too will take it forward to their communities and get inspired to hire individuals with disabilities to become co-facilitators. Morgan, Megan and the others are currently working on developing resources on leadership and self-advocacy. Megan ended the presentation with calling out to the members about the Train the Trainer that is scheduled to be launched on November 1st and 2nd and to spread the word about it.

Jennifer wanted to know if the webinar option is available and Megan affirmed that the online options can be made available. Jen requested that the details once finalized, be sent to her so that she could share it with the Council. Claudia enquired if the Train the Trainer option would be made available to waiver providers. Megan reiterated that they would like to get it across to as many people as possible. She added that a scripted curriculum book is provided to all participants.

Cathy wanted to know if they have had anyone trained in the program who then wanted to go to the gym but had trouble using the machines. Jen responded that one of the features of the program that each one chooses what works for them or suits their lifestyle. Claudia also enquired about program cost. Megan invited members' opinion on charging vs not charging; all members concurred that a reasonable charge of \$15-\$25 is acceptable since people are more invested in the program if they are charged. Jen added that they can publicize that scholarships will be made available.

Lindsey also presented Community Health Education Resources or Project CHEER. The purpose of the project is to address health disparities between individuals with and without disabilities through provision of educational opportunities that will provide resources for self-advocacy and help them make healthy lifestyle choices.

Lindsey invited members to offer their inputs and guidance to help take the project forward and for potential actors to star in the videos. Members also requested that the information be emailed to the members.

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

10) Kentucky Office of Autism update Amy Cooper-Puckett

The Office of Autism was created to provide a centralized location to coordinate state wide and regional efforts to enhance the quality of life and independence to individuals with autism and to support their families and caregivers; to improve coordination of autism resources and make

them available to families and self-advocates, to be a center of a communication network sharing autism related information among state agencies; and to provide administrative support to the Advisory Council on Autism Spectrum Disorder to unify and promote initiatives aimed at improving Kentucky's system of care.

Amy provided a historical review of events that eventually led Governor Bevin to sign the Senate Bill 185 into law on April 1, 2016. This law created new sections of KRS Chapter 194A to establish the Advisory Council on Autism Spectrum Disorder and create the Office of Autism. Amy then reviewed the vision and mission of the council and the names of the council members as of April 2016.

Some of the results of the collaboration that the Office of Autism has had include a joint grant application (UL, UK, ECU) for the LEND program and Regional Parent Summits. The next parent summit is scheduled for October 25-27, 2017 at Erlanger. Amy shared registration and conference details and the opportunity for attendees to earn eight and half hours of CEUs. CAC members appreciated the tremendous work done by the council and the various sub committees.

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

DD Council - Jen Hicks announced that the new Executive Director for the DD Council, Kellie McCain, starts this month. Two board positions will be opening in the near future. The Council is partnering with HDI and P & A to organize the showings of "Bottom Dollars" all over the state. The Council is expanding their contract with the Arc to bring out two magazines a year and reinstitute the Close Up program that sends middle school students to Washington DC to learn how to lobby. The Council has just renewed their contracts with HDI for projects including Health Partners, Peer Supports, Work Initiative, and Community of Sharing.

Protection & Advocacy - Camille announced the dates for the upcoming Medicaid Waiver public forums. There is a cap of 20 participants within each of these focus groups. Jennifer expressed concerns regarding the cap and Camille encouraged to send her feedback to Lori Gresham and/or Misty Peach at misty.peach@kentucky.gov. Camille is also working on organizing a showing of "Bottom Dollars" in Louisville simultaneously with the showing in Northern Kentucky on the day of the Annual Progress Report meeting. This meeting focuses on different issues each year; this year the focus is Disability and Poverty and is to be held on October 26th.

Division of Developmental and Intellectual Disabilities – Claudia informed the members that there are sixty slots currently left for SCL waivers. Claudia reported that this year is a budget session of the legislature, advocates may be interested in advocating for additional waiver funding as slots are limited. There are several committees working on the waiver redesign and Claudia invited members to share their input and feedback related to the 1915c waivers which include SCL, MPW, HCB and Brain Injury waivers. You are welcome to register for an upcoming focus group (announcement attached) or send written comments to:

MedicaidPublicComment@ky.gov

12) New Business and Announcements

Jennifer expressed her appreciation and gratitude to HDI for keeping everyone in the loop about new programs, services, and discussions and the positive effects of the ongoing sharing of the data and the discussions. Elaine seconded Jennifer's observation and underlined the importance of every CAC member spreading awareness of the information they receive within their own community.

Elaine moved the motion to close the meeting which Jennifer seconded. The motion passed.

Next CAC meeting: Monday, December 4, HDI Coldstream training room, 9:00 AM – 1:00 PM followed by a working lunch.