

**HDI Consumer Advisory Council
UK Coldstream Training Room
Monday June 5, 2017 9AM – 1 PM**

In attendance today...CAC members

Elaine Brown
Walt Bower
Cathy Jo Edwards
Maria Delgado
Jessica Whitehead
Traci Brewer
Jennifer Hicks
Cathy Lerza (in place of Claudia Johnson)
Kathy Sheppard-Jones
Vickey Reilly
Jennifer Ulbricht

Guests: Nellie Jones

Presenters: Meada Hall, Elaine Eisenbaum, Jeff White, Jacqui Kearns, Allie Rhodes, Darrell Mattingly

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

- 1) Welcome & Introductions Walt Bower

Walt Bower welcomes the Council. He is filling in for Jennifer Mynear as she is on vacation and Morgan Crawford who is ill. Members and guest introduce themselves.

- 2) Review and Approval of March Minutes Walt Bower

Minutes were reviewed. Jen Hicks moves to approve the minutes and Elaine Brown seconded the motion.

- 3) AUCD update - Council on Community Advocacy Jennifer Ulbricht

Jennifer Ulbricht provided an update on COCA. For the past 6 months COCA has been working on the advocacy leadership report. The second draft has been authorized and is under review. In addition, a new task force has been created to reach underserved groups called the Diversity & Inclusion toolkit provided by AUCD. At the last meeting COCA focused on updates, ongoing projects, and possible implications of President Trump's healthcare plan.

- 4) Community Work Transition Program update Meada Hall

Meada Hall, the director of the Community Work Transition Program (CWTP), gave an update on the program. She briefly discussed the history of the program as well as

changes with the passage of Workforce Innovation and Opportunity Act (WIOA) and its regulations that were distributed in August of 2016.

CWTP is one program with two options: pre-employment transition service (Pre-ETS) and transitions services. Pre-ETS is for all students who are potentially eligible, this means that they just simply need to have some form of documented disability and have not been through the OVR referral process.

The second option is Transition Services and is available for those students with the most significant disabilities; functional limitations in the areas of communication, interpersonal skills, mobility, self-care, self-direction, work skills, and work tolerance. If the student does not meet enough of the requirements they will be placed on a waitlist and not receive services, and this is why CWTP wants all students to start being served through the first option of Pre-ETS.

Pre-ETS is all about what the student needs currently has 5 services: Exposure and Experience Job Exploration, Work Based Learning, Post-Secondary Counseling, Workplace Readiness Training, and Self-Advocacy. Meada went into more detail about each of these services and how billing and reimbursements to schools work. She answered questions from the Council if they are counseling about managing Social Security benefits, questions on accessible workplace environments, and at what age these services are typically provided.

Meada explained the second option of Transition Services. The services provided in this option are vocational assessment, job placement report, employment follow-up, transition planning meetings, and transition exit meetings. Because the eligibility requirements are higher for this service Meada suggested that students do not move to this option until they have completed Pre-ETS and know exactly what job they want. She explained that some students may stay in Pre-ETS their whole high school career.

5) Partnership Planning Grant proposal

Elaine Eisenbaum

Elaine discussed how HDI is planning to apply for a new grant specifically for UCEDDs. It is called the Minority Serving Institutions Partnership Planning Grant. The purpose is to create a partnership between HDI and minority serving institution. Overall, the goal is to provide culturally competent services and supports.

The population that HDI wants to work with is veterans because there is a high veteran population in KY (10.5%) and they are less likely to complete college even with supports. Also families are less likely to access Medicaid services for their family members with DD. This is in part due to frequent moving. Elaine asked the Council for input on this question, "What are the needs of military families who have family members with IDD?"

A suggestion was that waivers are inaccessible because the waitlists are so long and military families move before they have access. There are few if any day program

services on base or special education services especially at smaller bases. What is available through Tricare does not provide services like a waiver would, though Tricare might be able to be modified to provide some services. OVR counselors have worked with Ft. Campbell, but the system is too slow and families move in and out quickly. There was at one point a discussion of a rapid response systems for VR as turnaround time is 60 days so it could be months before they are serviced, however no rapid response system is in place currently. The Council members also discussed flagging families with IDD move so that an automated email would be sent to service providers before the family even moves. There was a general consensus of approval of the idea of a pilot program to test a rapid response system.

After this feedback, Elaine reviewed the 8 goals of the partnership. She stated that not all of those goals need to be used but this is just a start. She asked the Council to review these 8 more specific goals and discuss which of them will help reach the overall goal of providing “culturally competent” services and supports through increasing diversity of leadership in the DD field.

Cathy Jo discussed improving the paperwork transfer system by using a color code method to improve transition services delay. There was also the suggestion of setting up general training through the sharing of training prepared by HDI and training already in place at the Veterans Office. This sharing of training would help with the cultural competence capacity. Another suggestion was to build an advisory committee of veterans and include outreach clinics in the more rural areas of the state. It was noted that Tricare already tracks families with children with disabilities, so it was suggested they use that system to send out resource information to families already identified. Others suggested working through the school systems established on base and building off of the partnership made with the Veterans Center on UK’s campus.

Elaine explained that the grant required letters of support or testimonials. She asked for suggestions of people who might be able to do this. Council members recommended going through the Representative of Veterans Affairs. Jen Hicks offered to look into this for Elaine.

6) Kentucky Works Project update

Jeff White
Kathy Sheppard-Jones

Jeff White reviewed the KY Works Project and explained that HDI is the grant holder but the project is a collaboration including 8 other organizations and partnerships are expected to grow over the next 5 years of the project. The goal of this project is to improve positive post-secondary outcomes for individuals with the most significant disabilities by 20% over the next 5 years. The three specific populations that this project is targeting are students with ID, ASD, or Multiple Disabilities because these three categories of IDEA have the worst post-secondary outcomes.

Jeff reviewed the specific context of Kentucky in which this project is working. In conclusion, he stated that around 70% of the total population in Kentucky has some

connection with an individual with a disability. This is significant because that is a huge business market. If people know that a business supports people with disabilities and hire them then they will support the business.

Currently the project is working on getting the 9 Special Educations Service Districts on board as a way of consolidating the 173 school districts in KY. The project is also analyzing existing employment policies and determining the extent to which they promote or create barriers for integrated employment. One way the project is improving policies is creating an executive order from the governor's office to set the standard of integrated, competitive employment. Also community conversations are being held. The last one was in Morehead asking parents, professionals, and self-advocates about creating meaningful employment opportunities in their community and how the project could work together with the community to make this happen.

Kathy Sheppard-Jones expressed gratitude towards the Council because they have been providing input since the beginning with the grant proposal. She encouraged the Council to continue their involvement in the KY Works Project and said at the next meeting they would be oriented to the website.

A few members of the Council asked how the project is getting buy in from employers. Jeff explained this is the next step in the project and he gave examples of how this was done in Louisville and the Disability Workforce Coalition. There was concern expressed by a member of the Council that what was done in Louisville would not be successful in the eastern part of the state. There was discussion exploring the option of funding transportation through respite to train students in Louisville and then take those skills back home to the workforce.

7) Break

8) Teaching Age-Appropriate Academic Learning via Communication Jacqui Kearns

Jacqui Kearns gave a presentation on the TAALC project. She reviewed how most students use oral symbolic language for the alternate assessment and that there is a problem because the rates of symbolic language used on the alternate assessment do not improve as students advance through high school. This means that even though many of these students have been receiving services since they were young they are still leaving high school without symbolic language.

TAALC is attempting to improve this through a 3 tiered system of training. The first level is basic training in communication explaining that communication and compliance are not the same. The second level involves training in communication identification and language development. The third level is specialized intervention involving training, coaching, and technical assistance to advance the level of symbolic language use. Jacqui provided initial evidence that the rates have improved and that the project is impacting students as they are improving from pre-symbolic to symbolic communicators.

Council members from western Kentucky expressed their concern that students are not qualifying for assistive technology in Western Kentucky. The Council members also discussed problems that no one follows through on the recommendations and follows up with the technology once students do receive it. Another issue is that parents do not even know of simple systems that exist.

Jacqui suggested that Jennifer Ulbricht and Elaine Brown fill out TAALC applications and bring the needed changes to their district. She also demonstrated Core Vocabulary as an alternative to PECs. Jacqui concluded that communication is a civil rights issue and it needs to be connected to academics. She also asked Walt to send out the resource from msd1stop.org to the Council.

9) KY-TASH

Allie Rhodes
Darrell Mattingly

Allie Rhodes and Darrell Mattingly presented on KY-TASH. Its vision at the national level is a world in which people with disabilities are fully participating members of their communities. There is a focus on individuals with ID and DD, but TASH is an advocate for all persons with disabilities. Allie identified the mission and overviewed the objectives that need to be accomplished in order achieve the vision.

TASH encourages research (*Research to Practice for Persons with Severe Disabilities*), host conferences, improved access to resources, and works on federal policy. In Kentucky, TASH is maintaining and strengthening federal agency and congressional relationships, as well as providing scholarships to help off-set expenses for attending the TASH-conference. There is a goal to really reach out to families and therefore they are working on workshops on supported decision making and faith community inclusion.

The presenters asked how they could include the CAC and what workshops that the CAC would be interested in. Council members suggested accessible workshop presentations on YouTube through access codes. Members of the CAC were interested in workshops on communication and supports in the school and Universal Design for accessible workplaces.

The Council also discussed barriers of workshop times and suggested Saturday workshops as being a more viable option for parents. Another suggestion was adding a nominal fee to boost numbers. Cathy Jo suggested the use of a community center in Montgomery County for workshops because she has a connection to that space. There were also suggestions of breaking siloes by inviting multiple organizations such as the Spina Bifida Association of Kentucky, DSACK, Autism Society of the Bluegrass etc. This would be more efficient for presenters and allow for breakout sessions. The final suggestion was setting up booths at hospital and school fairs.

10) New Business and Announcements

Walt Bower

There was no new business to report.

11) Agency Updates (DD Council, DDID)

DD Council - Jen Hicks is looking for more geographic representation from the eastern and western part of the state to serve on the DD Council. There is good representation from the central part of the state. Yet, there is not enough representation from the eastern and western parts of Kentucky. Jen has emailed Walt and Kathy to share the applications. Currently there are 28 positions available. The expectations of these positions include: attendance quarterly meetings that meet for two days, be involved in a work team, and attendance at the committee meetings.

Jen noted that the executive director resigned. The executive committee is going over applications and that position should be filled by the end of the summer. The board has become more geographically diverse and with a larger age-span of representatives, but there is still work to be done. There is a new contract with P&A to see what questions are coming through about ABLA accounts. Jen closed by stating that DD Council is moving to a new location in September.

Division of Developmental and Intellectual Disabilities - Cathy Lerza stated that the SCL waiver has been renewed through February 2022. Now 240 individuals that were on the waitlist have been allocated. Currently, 2 people are on the emergency waiting list, but they will be off in July. There has been progress on redesigning all of the Kentucky waivers.

12) Lunch and Further Discussion about CAC Members' Involvement in HDI Project (12:00 – 1:00) All

Jessica Whitehead motioned to end the meeting and Jen Hicks seconded the motion.

Next CAC Meeting: Monday, September 11, HDI Coldstream training room, 9:00 AM 12:00 PM followed by a working lunch.