## **HDI Consumer Advisory Council Minutes Coldstream Training Room** Monday December 1, 2014: 9 AM - 12 PM

## In attendance today...CAC members

Lee Gordon

Harold Kleinert

Shannon Caldwell

Paula Caldwell

Morry LaTour

Jonathan Compton

Claudia Johnson

Hazel Forsythe

Allie Rhodes

Walt Bower

Cathy Jo Edwards

Jennifer Crawford

Elaine Brown

Jessica Wolfe

Jennifer Mvnear

Camille Collins

**Guest:** Ruth Caldwell

**Presenter:** Carolyn Wheeler

**Technical and other assistance** provided by Dave Flechler and Judy Johns

1) Welcome & Introductions (9:00) All members introduced themselves.

Paula Caldwell

- 2) Review and Approval of September Minutes (9:05) Paula Caldwell The minutes were reviewed. Motion to approve by Morry and seconded by Claudia.
- 3) AUCD Update – Council on Community Advocacy And AUCD Conference (9:10)

Shannon Caldwell Paula Caldwell Harold Kleinert

Shannon reported he had a great experience on the AUCD Council on Community Advocacy (COCA). Association of University Centers on Disabilities (AUCD) Board members may only serve one 3 year term, so Shannon rotated off the AUCD Board this year. Harold remains as AUCD's treasurer. Harold reported Shannon was recognized with one of the awards for meritorious service at the Awards Ceremony at the AUCD national conference in Washington, D.C.

4) Status of Annual DD Network Meeting (9:20)

The Kentucky Self-Advocates for Freedom had their annual conference last March in Louisville. This year it's going to be in Lexington. HDI, the DD Council, and possibly P &A are looking at doing an event together as a part of the Kentucky Self-Advocates for Freedom Conference. We will again sponsor CAC members who wish to attend the KYSAFF conference.

5) KY Peer Support Network Project Update (9:30) Harold Kleinert

Harold announced that the project has held regional trainings at every Co-op in the state. The project is working with schools throughout the state to develop peer networks with for students with significant disabilities.

6) Status of HDI Website Redesign And Review of HDI Website (9:35)

Jonathan Compton and Shannon Caldwell

Jonathan Compton reported a Website Redesign committee was established with 16 members. The committee has had 3 meetings with the larger group. The goal for the website roll out is May 1. Five subgroups were formed out of the larger group and they have been meeting monthly. The following is the progress by subgroups:

- 1) Accessibility Worked with Maria Delgado to make better use of headings on the homepage and better use of lists with alternative texts. The subgroup is also working through recommendations from Maria about accessibility.
- **2) Branding** Found the graphic design standards/web standards for the university and are working on creating a new logo for HDI. A short biographical introduction of each CAC member with a picture is planned. The project tab is currently repetitive and that will be updated.
- 3) Social media Creating a survey to see the best way to share news and information across the projects. Current news on the website will be updated at least on a weekly basis. A member of the subgroup spoke with the webmaster at Vanderbilt University and the webmaster has offered to provide further assistance with the redesign of the HDI website. In reply to a question about the Facebook page, Allie discussed pulling in other projects that have Facebook pages within the HDI Facebook page.
- 4) Technology Decided to use WordPress for the redesign of the new HDI website. The webmaster at Vanderbilt is also using WordPress on their website. There is a "template" or a "rough draft" of a new WordPress HDI website. The Website Redesign committee was able to view the rough draft.
- 5) Content Described the findings of a survey to all PI's on their ideas for the website and what they would like to see. Some recommendations were to pare down the information by stakeholders and grouping information by themes.

7) Evaluating the Impact of our Work – Seeking CAC Input (9:50)

Allie Rhodes and Harold Kleinert

The members were asked to provide their input to the evaluation of HDI activities in five major areas. An informative, creative, and collaborative discussion from CAC members followed! The members addressed the following question for each major area, "What are other questions that measure success?"

- 1) Pre-service training A member suggested two further questions: (1) What do employers say about the effectiveness of the students? (2) What do audiences or the people they serve say about the effectiveness of students? A member commented that a student may rank a program highly simply because it's the nice thing to do, but another way to measure success is to ask what the employers think about the students.
- 2) Training One member asked, "Would starting transition experiences, such as social etiquette, early before high school get you better results?" Another member asked, "Is there an ability to track success over time and to see if there are roadblocks along the way?" Other questions were: What is the longitudinal impact? Are there ways to sustain it? If you took the funding away, would the changes still be there? Can you really track it long term? Are the participants who received the training having their quality of life changed regardless of what the community thinks about the training?
- 3) Technical Assistance A member asked, "Is there an expectation that you will get regular assistance or is it something you have to request?"
- 4) Research A member suggested, "What if you ask people about their quality of life and then track people longitudinally to ask how we are doing?" Another member raised multiple questions, "What time of year are they asking participants about when they are depressed? If the question is asked during the winter, it's possible you may get a different answer than if the question is asked during the summer. Are people more depressed in the winter? These are factors that need to be considered."
- 5) Information Dissemination In reply to the discussion of online training modules, a member asked, "Are the modules really accessible and is it applied to real life?" Other questions raised were: What if you ask the question at the end of the survey and have participants evaluate the product? What if you have an attachment to the product that will take participants back to the website and then have them complete a survey? Could you have focus groups in the community and ask participants for feedback to see if those products are useful?

Break (10:25)

8) Project Spotlight – KY Sibling Leadership Network Carolyn Wheeler And Futures Planning (10:35)

Carolyn Wheeler provided an overview of the Special Needs Trust with Life Plan of Kentucky. The Special Needs Trust is an attempt to provide for people with disabilities and their families an ongoing trust that provides for persons in perpetuity. The purpose of the Special Needs Trust is to make available to families to leave money for their son or daughter without affecting services or disqualifying people for benefits. Carolyn also announced the National Sibling Leadership Network (SLN) will be held in Louisville on May 30 and May 31, 2015. Siblings tend to outlive their parents by about 20 to 30 years, so the SLN provides siblings of individuals with disabilities the information, support, and tools to advocate with their brothers and sisters.

9) Review of Membership Status and And Current Terms (11:20)

All

There are no major changes as of now. However, there will be significant changes to be made in a year from now, as 4 self-advocates rotate off the Council next year. **Please contact Shannon** if you know someone who is willing to serve.

10) Election of New Vice-Chair and Setting of All 2015 Meeting Dates (11:25)

Harold nominated Cathy Jo and she accepted the nomination. Morry nominated Allie. However, student members may not serve as the Vice-Chair. Shannon nominated Elaine and she declined the nomination. The motion to elect Cathy Jo as the new Vice-Chair was seconded by Allie and the motion passed. The new meeting dates for 2015 are March 2, June 1, September 14, and December 7.

11) Agency Updates (P & A, DD Council, DDID, DVR, CCSHN, State ADA Office) (11:35)

Each Agency

**Division of Developmental and Intellectual Disabilities** — Claudia Johnson reported that the KY Department for Medicaid Services asked for input on the Home and Community Based rule for all the waivers. The opportunity for comments will have closed Friday, December 5. Claudia also announced that all state owned property went tobacco free. The DDID is the process of looking for a new director and House Bill 144 is in need of self-advocate members.

**Protection and Advocacy** – Camille Collins reported an overview of activities from the last quarter. P & A achieved the following activities this past quarter:

For July-September 2014, there were 537 informational and referral activities, including questions about providers' rights. There were 20 trainings provided and 517 individuals received training with a staff of only 25 members.

*Michelle P regulation was amended after submittal of comments.* 

Filed comments on KY's revised Olmstead Plan.

Met with State Board of Elections and Inclusion Solutions re: "Ballot Call" an accessibility device used on election days.

Attended DD Council Meeting.

Submitted written comments on the Home Care regulation amendments.

Presented an overview of guardianship law to DD Network.

Planning with Center for Accessible Living for the Accessing Your Power event for 2015.

Continued work on patient liability.

Attended and presented at Project Safe 2015.

Provided employment training to over 50 individuals at Employment Solutions.

Held public forum at the Latino Festival in Lexington, KY.

**Commission for Children with Special Health Care Needs** – Lee Gordon announced Debbie Gilbert and Sondra Gilbert are continuing to work on the Parent to Parent Project and the Commission is collaborating with HDI on the KY Peer Support Network project.

- 12) New Business and Announcements (11:50) Paula Caldwell *There was no new business to report.*
- 13) Special Recognition (11:55) Harold Kleinert Harold, on behalf of the CAC, recognized Paula for her outstanding service as our CAC Chair in 2014.

## NEXT CAC MEETING: Monday, March 2, Coldstream 9:00 AM – 12:00 PM, followed by a working lunch.

Allie made a motion to adjourn the meeting and Jennifer seconded.

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