



Consumer Advisory Council

Meeting Minutes

Monday, December 5, 2011

Members present:

Sandra Duverge	Chastity Ross	Jeff Edwards	Harold Kleinert
Megan Baker	Jessie Birdwhistell	Jason Jones	Fannie Stonestreet
Morry LaTour	Malkanthie McCormick	Paula Caldwell	Shannon Caldwell
Claudia Johnson	Hazel Forsythe	Peter Perry	

Guests and Staff: Daniel Livingston, Marybeth Vallance, Christina Espinosa

Welcome and Introduction

Malkanthie McCormick welcomed the members in attendance and called the meeting to order. Members introduced themselves to the group.

Review and Approval of August Minutes

The minutes from the June CAC meeting were reviewed, voted on and approved.

AUCD Update – Council on Community Advocacy/AUCD Conference

Shannon Caldwell reported that the annual AUCD conference took place Nov. 2-5. It was the 40th anniversary for AUCD; a lot of workshops about past, present, and future. Shannon was elected to the Board of Directors of AUCD and became the Family Co-Chair of COCA (the Council on Community Advocacy). He expressed his excitement to represent and advocate for families of individuals with disabilities across the country. He said over the next few years, COCA would like to get more self-advocates and family members involved at the national level. Shannon also mentioned the international civil rights issues that COCA was concerned with. AUCD has drafted a letter to the Senate promoting a bill of rights for individuals with disabilities around the world. COCA is also discussing the possibility of individuals with disabilities having a universal ID for public transportation services. Several individuals in the CAC opposed the idea of identifying or providing discounts to people with disabilities. Several questions were raised about the purpose of the ID card, which Shannon was not sure about, as the universal ID card idea is in the early stages of development. Marybeth Vallance mentioned that the card could possibly be related to standardizing transportation guidelines across the nation. Several other possibilities were mentioned, and Shannon said he would share people's concerns and provide a more detailed report at the next meeting. For more information, contact

Shannon at (606) 330-1702 (home), (606) 524-6670 (cell), or email sjgc14@windstream.net.

Harold discussed the AUCD conference; said HDI is the only UCEDD that now has two representatives on the board of directors: Dr. Kleinert and Shannon Caldwell.

DD Network Joint Transportation Target

Dr. Kleinert reported that this Joint Target is dealing with improving transportation services in rural areas for individuals with disabilities. Shannon mentioned that, even with Medicaid, medical and non-medical transportation is just too costly. He mentioned several possibilities, such as creating an account to help offset the cost.

HDI Transportation Provider Training Update

Morry LaTour reported on the consumer training session with LexTran bus drivers (this training included Andrea Strassburg, Darrell Mattingly, and John Glisson as panelists). In the session, panelists shared special needs and considerations of some individuals with drivers and how they can best help people with disabilities. The CAC discussed the driver training module, created by HDI, which is proving very beneficial for public transit driver training. Harold Kleinert said there were around 60 drivers that had already taken part in the online driver training modules. He said there were no studies so far on the impact of disability training on driver behavior; we would like to collect these data and use the results to educate other cities/areas. Morry also mentioned that Wheels has a new director, whom he has met with about possible training opportunities.

Developing Family Mentorship Possibilities with Asbury and Pediatric Residents

Marybeth Vallance reported that she had a meeting with Asbury, and that HDI was invited to teach a disability awareness class at the university. She would like to pair the family mentors with seminary students. She reported that she was also trying to pair UK pediatric residents with family mentors. She also reported that the mentor mothers held an hour-long panel for pediatric faculty and residents as part of UK Grand Rounds, which was very helpful. She was asked to organize more panels in the future.

Project Spotlight: Home Modifications Project

Christina Espinosa discussed the HAMS home modification project, funded by the Money Follows the Person Grant, which has been extended through 2020.

Claudia Johnson asked for clarification and we learned that houses must be up to code before being eligible for Home Modification funds

Chastity Ross asked if these funds were only for people moving out of facilities; they are.

Malkanthie McCormick asked if the BBB was consulted about contractors that are considered for the Home Modification projects.

Christina noted that 10% of the value of the home, up to \$15,000, is available to modify each home (i.e., the more expensive the home, the more funds there are to modify).

Hazel Forsythe asked if there was a list of contractors with whom HAMS has worked which could be distributed to the CAC and individuals/families. Christina said she would get that together and distribute to the group.

(Break)

Nominating New Members for CAC

A list of current CAC members and their terms was distributed. Dr. Kleinert said that a process needs to be set up to replace members who are rotating off the Council. Federal regulations require racial and geographic balance, as well as representation of a wide range of disabilities, so members from Western or Northern Kentucky should be recruited. Dr. Kleinert asked that anyone who knew someone from those regions who would be interested in serving should ask them if they would be willing to serve, and if so, forward their information to the nomination committee. The nomination committee consists of Peter Perry, Sandra Duverge, and Shannon Caldwell (and Karen Boudreaux if she is able to serve). Sandra Duverge mentioned that it might be difficult to identify people in those regions since nearly everyone on the Council is from other regions. She suggested contacting regional organizations like First Steps to find eligible candidates. **Names should be forwarded to the Shannon Caldwell by January 1, and recommendations will be made by the Nominating Committee at the March CAC meeting.**

Consideration of Video-conferencing future CAC meetings

The Council discussed the possibility of video-conferencing the meetings from the Coldstream office instead of the current location. Claudia Johnson added that video-conferencing would improve the attendance and make it easier for people from Western and Northern Kentucky to participate. Hazel Forsythe suggested a few technological options, including ConnectPro (UK has free access available) and Facetime with the iPad. Potential issues were discussed, including quality and connectivity issues, and making sure people understand they are still welcome and encouraged to attend and do not *have* to participate in the video-conference aspect. Dr. Kleinert clarified that the video-conferencing would only be beneficial for people who would otherwise be unable to attend. The Council agreed that changing of the location of the meeting to the Coldstream office would be a good idea.

Election of new CAC Vice-Chair

Chastity Ross, the current vice-chair, will become the chair next year, so a new vice chair must be elected. Sandra Duverge was nominated, but declined. She nominated Morry LaTour, who accepted. The nomination was seconded and voted on, and Morry LaTour was elected the 2012 CAC vice chair.

Setting 2012 CAC meeting dates

Dr. Kleinert announced the dates for 2012 CAC meetings. **The March, June, and December meetings have been scheduled for Coldstream.**

Monday March 5

Monday June 4

August Joint Meeting TBA

Monday December 3

CAC consideration of Sequenom/Down Syndrome testing

The Council was asked to discuss the implications of a new non-invasive, and much more accurate prenatal screening test to let mothers know whether their babies had Down syndrome. Dr. Kleinert brought up the question of what mothers would do with this information. With a lot of misinformation about what having a child with Down syndrome means to a family, he pointed out that it is essential that mothers and families are provided with accurate, balanced information about Down syndrome. Malkanthie McCormick voiced concerns of where these types of tests could lead to in the future. Harold showed a draft of a letter to be sent to the company that makes these tests, asking for them to ensure balanced information and that women know it is their choice to have (or not have) the test done. To view the draft of the letter, see Appendix A. Dr. Kleinert made a motion to send the letter from the Council as a whole, and the motion was seconded and approved.

Agency Updates

Jason Jones from the *Office of Vocational Rehabilitation* reported that Dave Beach was elected as acting executive director during transition period; OVR is gearing up for another 4% cut in funding, which will affect the number of people who can receive benefits. OVR is in danger of being absorbed into OneStop services, which will make it more difficult for individuals with disabilities to understand how to access OVR services.

Claudia Johnson, *Department of Behavioral Health, Developmental and Intellectual Disabilities*, reported that the final public forum for family members and other stakeholders about the SCL and MPW changes will be December 7 at Kaleidoscope in Louisville from 6-8 pm. She also reported that SCL Regulations are being drafted and will be shared with HB 144 when complete. The Revised Case Management training for DD waivers will begin in December and will be offered across the state throughout the next year for all new and current Case Managers. The Health Risk Screening Tool is being rolled out, and initial training for DDID and agency staff began on this tool in November. Benefits Analysis training is being provided around the state by DDID benefits analysts and has been well attended. Hopefully this will encourage increased usage of supported employment in the waivers. Finally, Claudia reported that DBHDID has formed a state team for the Alliance for Full Participation with a goal of doubling employment for people with disabilities. Partners from CCDD, P&A, OVR, DOE, HDI and KSAFF attended the national conference in November.

Jessie Birdwhistell, *HDI student representative to the CAC* and doctoral candidate, reported on her study of the quality and perceptions of classroom relationships for students with autism, and how these relationships are perceived by the students themselves, their classroom peers, and their teachers. She wants to examine relationship maps from all students within a classroom, and survey their knowledge of autism.

Special Recognition

Dr. Malkanthie McCormick was recognized and presented with a certificate for her service as 2011 CAC president.

New Business and Announcements

Hazel Forsythe mentioned that equipment will need to be upgraded before video-conferencing is enacted for our CAC meetings.

Shannon Caldwell noted that the Statewide Independent Living Council will be having a meeting soon. He will email information about the meeting to the listserv.

Harold recapped the actionable items before the next meeting: 1) providing nametags for CAC members at all of our meetings, 2) moving the meetings to Coldstream, 3) looking into video-conferencing options, and 4) getting with the DD council and P&A about writing a letter concerning OVR's restructuring issues.

The meeting was adjourned.

MARK YOUR CALENDARS - UPCOMING 2011 CAC MEETING DATES:

**Monday, March 5; HDI Coldstream Office,
1525 Bull Lea Rd. Suite 160, Lexington KY 40511**

**Monday, June 4; HDI Coldstream Office,
1525 Bull Lea Rd. Suite 160, Lexington KY 40511**

**Friday, August TBA (Joint Meeting with Protection & Advocacy and the DD
Council) 9:00 AM to 2:00 PM; Embassy Suites, Lexington**

**Monday, December 3; HDI Coldstream Office,
1525 Bull Lea Rd. Suite 160, Lexington KY 40511**