



University Center for Excellence in Developmental Disabilities

Consumer Advisory Council

Meeting Minutes

June 6, 2011

Members present:

Shannon Caldwell	Hazel Forsythe	Karen Boudreaux	Harold Kleinert
Paula Caldwell	Chastity Ross	Jason Jones	Fannie Stonestreet
Pam Mattox	Pat Seybold	Lee Gordon	Kerri Wells
Milt Tyree	Morry LaTour	Malkanthalie McCormick	
Megan Baker	Jason Jones	Alan Wells	

Guests and Staff: Marybeth Vallance, Ashlea Doyle, Janah Arvin

Welcome and Introduction of Council Members

Malkanthalie McCormick, CAC Chair, welcomed the members in attendance and called the meeting to order. Members were asked to introduce themselves to the Council and sign their names on the attendance sheet.

Review and Approval of March Minutes

The minutes from the March meeting were reviewed, voted on and approved with no corrections. Morry LaTour made the motion to approve the minutes and Marybeth Vallance seconded the motion. (A later correction was made to the March minutes to add Chastity Ross to those in attendance, as she had been inadvertently omitted).

AUCD Update – Council on Consumer Affairs

Shannon Caldwell, CAC-COCA liaison, gave his report as COCA (Council on Community Advocacy) representative. He reported that COCA held a conference call Thursday, June 2nd. COCA members have started to work on a proposal regarding the value of a universal identification for consumers who use transportation providers. Lee asked for clarification of the reason behind this proposal. Shannon explained that the Council was proposing to see various models of passes and that they could perhaps standardize pass information to make consumer needs and passes more universal and that accommodations for individuals' needs may be clearer to alert drivers.

Shannon described COCA's goal of supporting the House of Representative's proposed law regarding protection of the rights of individuals with disabilities re international issues. He will send out a letter of support to CAC, with the recommendation that members contact their Senators. Malkanthalie asked for clarification, and Shannon explained that it was much like the ADA with rights concerning dignity and safety.

Shannon also noted that as this fall meeting would be AUCD's 40th Anniversary, COCA was working on show-casing achievements of members and actions of COCA and AUCD. Harold reported that he would contact Norb Ryan to request his historical input as being a long-time leader of COCA.

Shannon reported that COCA has 2 co-chair position openings – 1 for a person with a disability and a 2nd opening for a person having a family member with a disability. Shannon was submitting his interest in being nominated in the 2nd capacity. The vote will take place at the AUCD fall meeting. Shannon reminded members that he would continue to send out alerts and emails to CAC members regarding federal budget issues. On a personal note, Shannon added that his mother had knee surgery last Wednesday, and was walking a short distance with assistance. Dr. Kleinert asked Shannon to relay well-wishes to her from the entire CAC membership!

DD Network Joint Transportation Target

Shannon gave the report on this rural transportation initiative. A 2nd meeting will be held June 24th at 1 pm in Frankfort. He reminded members that the Committee had worked with a state-based group to collect statewide information regarding rural and metro transportation providers. Pat Seybold, Paula Caldwell, and Karen Boudreaux also serve on this Committee that Adam Jones of the DD Council chairs.

HDI Transportation Provider Training Update

Marybeth Vallance and Harold jointly discussed this training module project which will ultimately be on HDI's website for public transportation driver training on ADA issues. Harold noted that our technical contractor is using the Preservice Health Training modules as a structural framework for the Transportation Module, to give it the same look and feel. Marybeth expressed appreciation for LexTran's full support with providing 2 drivers, their administrative staff, and a bus to be used for a full day of filming driver talking points and consumer-driver segments, which supplement the other vignettes filmed last spring at the initiative of the CAC.

Jason suggested that the availability of this final training module for transit drivers be shared with university transit companies for ADA training and Morry, who was also filmed in a segment, suggested that we send a copy to Easter Seal's Project Action. Malkanthie asked if the web-based module was intended to be used on a regular basis with drivers as ADA training and if the module had any opportunity for user or reviewer feedback. Marybeth explained that transit companies could use this universal transit driver training to train new drivers or use to remind drivers of ADA issues on an annual or correction measure basis. She noted that speaker talking points or screen information can be updated and inserted into the web-based training module. Harold acknowledged that there is a text box, but we can also add a feedback survey to the end of the module.

KY Supported Employment Training – Family and Self-Advocate Web Page

Milt Tyree reported showed the updated Supported Employment Training Project Web page dedicated to job seekers and their parents which was requested by CAC members. He noted that Jason, Karen and Malkanthie had given their helpful input into the web

page which has been a work in progress since December. Milt explained that he did add an additional piece under “Frequently Asked Questions” about issues of student pay during school to work transition. He added the U.S. Department of Labor guidelines for work transition programs.

He showed the link to the personal stories involving Mallory, Daniel and Alex but he cautioned the he cannot go “live” with this link as there were still some permissions’ needed. He explained that each story ends with “Lessons Learned.” He noted that each supported employment story is “ordinary”, not perfect, but a person-centered work in progress. Malkanthie commented that many parents are still unaware of payment issues affecting work during school and impact to SSI, SSDI and consumers drawing benefits through their parents. Milt noted that the site has basic information about SSI, Medicaid, and Disability.

Shannon asked if he can share with COCA, the Transportation Module and this consumer education web-page. Milt and Harold noted agreement regarding sharing both projects after they were completed, with required permissions.

Developing Family Mentorship Possibilities with Asbury

Marybeth reported the she and Milt had held a very productive luncheon meeting with primarily the Social Work faculty of Asbury University on April 11th. The faculty did seem very interested and asked many questions about the programs and research projects of HDI. Marybeth had been invited and did present a 50 minute power point and video presentation to Professor Steve Dawson’s “Introduction to Social Work” class, which was also attended by the coordinator of the Social Work curriculum, and an MSW student who had worked with Riding for Hope. Steve extended the invitation for Marybeth and Milt to return to be a part of teaching his fall 2011 “Introduction to Social Work” class and commented on how well the historical and consumer issues of disability awareness had worked into the class curriculum.

As a faculty representative of Asbury Seminary was not able to attend the collaborative lunch meeting, Marybeth has sent another request to Dr. Bill Descouteaux of the Seminary requesting an opportunity for Milt and her to return to meet with the Seminary staff about possible infusing consumer issues and concerns re faith inclusion into their well-recognized curriculum.

Milt noted that he has some connections to the 2 Seminaries in Louisville and Marybeth promised to visit the Lexington Theological Seminary Professor, Steve Monhollen, to see if he was still interested in Mentor Families doing even an on-line panel presentation to their newly-structured on-line Seminary and Pastoral Counseling program. Karen discussed that the Catholic Dioceses could benefit from Mentor Family personal stories of faith inclusion and Paula noted that she and Shannon would like to be included as part of any panel or mentoring projects with local or regional faith-based communities or Seminaries.

HDI RESEARCH UPDATE – Discussion of Meaning and Impact of HDI and Student Research

Harold distributed a copy of his Power Point presentation on the impact of HDI's research and explained that HDI areas of research included alternate assessments and access to the general curriculum for students significant cognitive disabilities; education in developmental disabilities for health professionals and students; and the impact of early childhood training for providers of day care and early childhood trainer credentialing, as well as outcome data regarding early childhood transitions. HDI had created the first statewide alternate assessment for students with significant disabilities in the US in 1992 and KY was the first state to include "all" students in measures of educational assessments and accountability. As a result, KY's HDI took a lead role in both research and providing technical assistance in this field.

He discussed recent research published by both HDI staff and research assistants. He also noted that HDI had participated in a physician review trial with 16 major residency programs in further reviewing the impact of "Brighter Tomorrows" on teaching physicians how to share the news and present the perspectives to parents both expecting and giving birth to a newborn with Down syndrome.

He explained the importance of UCEDDs having their research assistants and certificate students participate in research, and cited that at least 20 HDI students had published in national journals in the last 3 years. He also noted that HDI is doing research on recreation and the impact of extra-curricular experiences for students with significant disabilities, as well as faith-based family mentorships.

Harold explained the "Low Incidence Communication Initiative" which grew out of our analysis of our data base of nearly 13,000 students in 7 states. Results showed that only about ½ of students who needed augmentative communication (AC) were being taught to use AC as part of their educational program. The findings revealed concern that few students were progressing from "pre-symbolic" to "symbolic communication," despite a large percentage at an "emergent" level. He also showed a video of the impact after working just 6 weeks with a 16 year old youth who had not previously had any augmentative communication device.

In response to these data, the TAALC project at UK conducted pilot training for 4 districts with on-site training and weekly team coaching calls, with teams including special education teachers, speech/language pathologists, parents, administrators, and others. To date, we have trained approximately 75 – 10 school staff representing 14 student teams. Data shows significant positive changes for *ALL* students, regardless of initial communication level. The implication of this study has led HDI to work with the KY Department of Education to insure that students are never dropped from speech/language services for lack of progress. We actually hope to propose a change to the language in the re-authorization of IDEA, such that: *in the case of a child who does not yet have a symbolic mode of communication (oral language, augmentative*

communication system and/or manual signs) that the IEP team develop a plan for a communication system for that child as part of the IEP.

Harold discussed HDI's and some of the CAC members' roles in the collecting data on the National Core Indicators (NCI) and noted that the KY Division of Developmental and Intellectual Disabilities had asked HDI in 2010 to put together a team to analyze the data on almost 400 face-to-face interviews concerning what was going well and what needed to change for individuals receiving Supports for Community Living Services in our state. Issues of medications for behavioral control, health and exercise, loneliness and friendship, and employment were strategic areas needing critical and positive change. The Committee made recommendations to the Division in each of these areas, and these recommendations had an important impact upon the language of the proposed new SCL waiver recently submitted to the Center for Medicaid Services (CMS) for approval.

Dr. Kleinert then distributed hand-outs summarizing proposed changes to both the Michelle P Waiver and the SCL Waiver, sent by Claudia Johnson as part of her agency report. These proposed changes include significant rate increases to SCL providers who provide supported employment; and a new focus in person centered planning coaches.

Small Group Board Activity – Other Important Areas of Research

We broke into three groups to address these 4 questions related to Harold's presentation on research at HDI:

- What captured your interest and how can we expand our work into area of your interest?
- Can you think of specific questions you would want answered in these areas?
- How do you see family members and individuals with disabilities participate in that research?
- How would you see our CAC participating in our HDI research?

Reports from Each Small Group are included in a separate attachment.

Preparing for the Joint DD Network Meeting

Harold announced that this annual joint meeting will be a half-day morning meeting and end after a noon to 1 pm lunch on August 19th. As part of the research initiatives regarding advocacy for health and wellness, members will be encouraged to wear casual and comfortable clothing and will participate in an interactive exercise, health and wellness program. Hand-outs and information will be available to members to share with other advocacy groups and providers in their areas. The meeting will be located at the Embassy Suites here in Lexington.

Agency Updates –

Jason Jones of the ***Office of Vocational Rehabilitation*** noted that because of fiscally strong management, the OVR has been able to save sufficient funds to begin to address the needs of persons on their waiting list.

Lee Gordon of *the KY Commission for Children with Special Health Care Needs* reported that his agency is still recruiting families for their parent-to-parent initiative, especially in the eastern part of the state.

Pat Seybold of the *KY Council on Developmental Disabilities* noted the Council's public hearings on the proposed changes to the Michelle P and SCL Waivers, as well as the call for public comments to the Council's new Five Year Plan. She asked Harold to distribute these to our CAC members.

Special Recognition

Harold presented **Alan** and **Kerri Wells** with framed *Certificates for Leadership in Advocacy* for their six years of service to our Consumer Advisory Council (2005-2011), with the completion of their terms coming with this meeting. Alan also served as CAC Chair in 2010. The entire CAC thanked both Alan and Kerri for their years of service and advocacy.

Next Meeting – Friday August 19, 2011 – JOINT DD NETWORK MEETING, Embassy Suites Lexington